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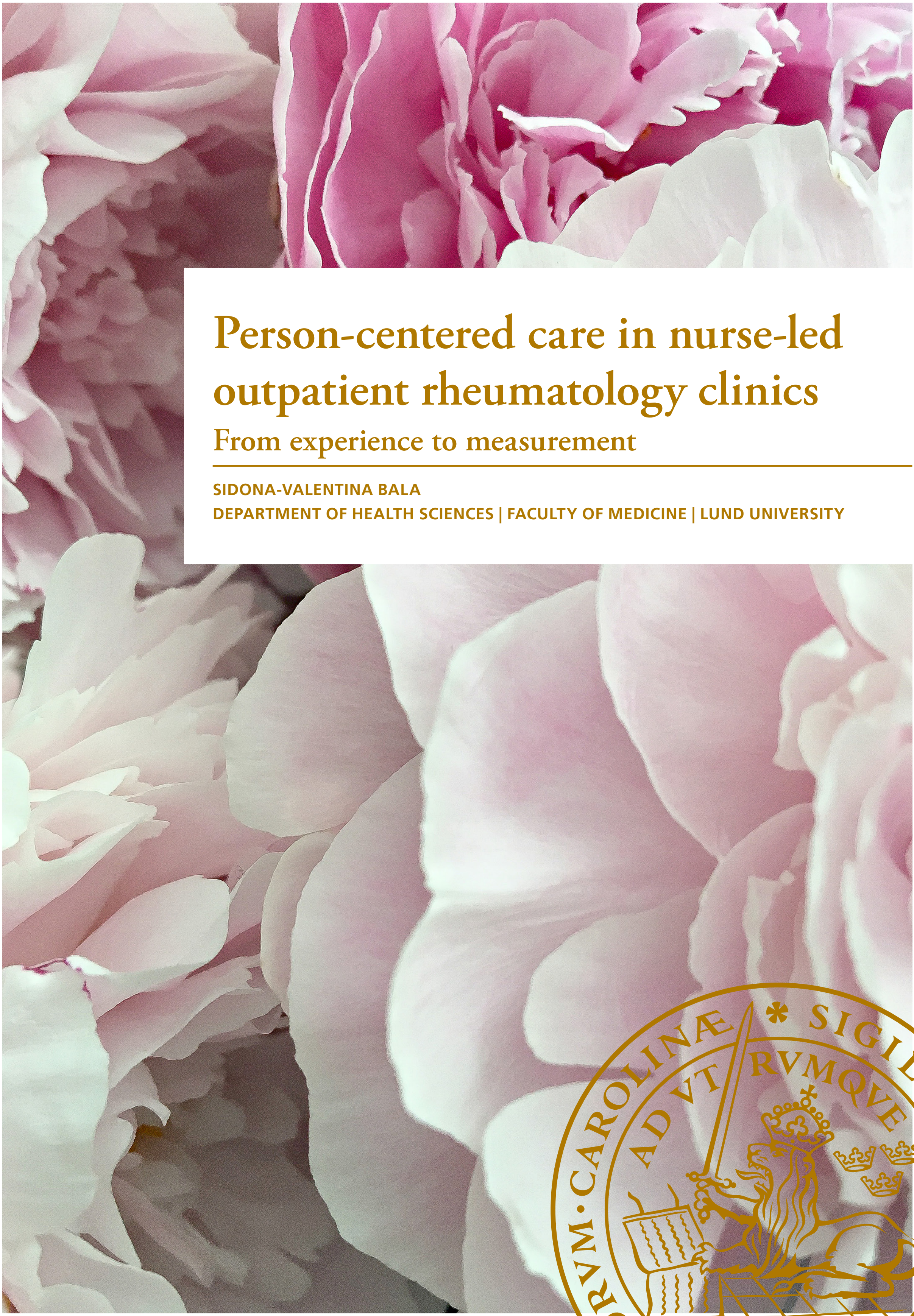

Person-centered care in nurse-led outpatient rheumatology clinics

From experience to measurement

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Sidona-Valentina Bala

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Person-centered care in nurse-led outpatient rheumatology clinics: From experience to measurement

Abstract

Aim: To describe and understand patients' experiences as a means to conceptualize and evaluate outpatient person-centered care (PCC) in nurse-led rheumatoid arthritis (RA) clinics.

Methods: Persons with RA were interviewed about how they experienced their nurse-led outpatient care and about the meaning of living with persistent RA. Interviews were analyzed by qualitative content analysis and hermeneutic phenomenology. Based on these results, existing PCC frameworks and hypothetical logical reasoning, a conceptual framework for nurse-led outpatient PCC was developed and used to operationalize a PCC instrument for outpatient care in rheumatology (PCCoc/rheum). Acceptability and content validity of the PCCoc/rheum were evaluated, and its measurement properties were tested according to Rasch measurement theory (RMT).

Results: The experience of nurse-led outpatient care was expressed as social environment, professional approach and value-adding measures, all relating to the degree of PCC. Living with persistent RA was revealed as an existence dominated by painful symptoms and treatment, radical changes and limitations in life, a continual struggle to cope with life and to master the illness, and a dependency on those who are close by and the world around. Results also pointed to the need for a stronger PCC approach. An outpatient framework was conceptualized with five related domains, and was used to develop the PCCoc/rheum, which showed good acceptability and content validity. RMT supported the accordance between the PCCoc/rheum and the conceptual framework, and its measurement properties were generally supported.

Conclusions: Experiences of persons with RA support a central role for PCC. The conceptual framework and the PCCoc/rheum have potentials to improve implementation and evaluation of outpatient PCC and contribute to quality of care from a PCC perspective in nurse-led rheumatoid arthritis clinics.

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To my beloved twin sons James and Mikael

Contents

The good life is one inspired by love and guided by knowledge.

Bertrand Russell

Abstract

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Abbreviations

BARFOT	Better Anti-Rheumatic PharmacoTherapy
CVI	Content Validity Index
DAS28	Disease Activity Score calculated on 28 joints
DIF	Differential Item Functioning
ESR	Erythrocyte Sedimentation Rate
EULAR	European League Against Rheumatism
FDA	Food and Drug Administration
HAQ	Health Assessment Questionnaire
HCPs	Health Care Professionals
ICC	Item Characteristic Curve
I-CVI	Item level Content Validity Index
NLC	Nurse-led Care
OECD	Organisation for Economic Co-operation and Development
PatGA	Patient's Global Assessment of disease activity
PCC	Person-Centered Care
PCCoc/rheum	PCC instrument for outpatient care in rheumatology
PREM	Patient-Reported Experience Measure
PSI	Person Separation Index
RA	Rheumatoid Arthritis
RMT	Rasch Measurement Theory
S-CVI	Scale level Content Validity Index
SJC	Swollen Joints Count
TJC	Tender Joints Count
UK	United Kingdom
VAS	Visual Analogue Scale
WHO	World Health Organization

Original papers

This thesis is based on the following four papers, referred to in the text by their Roman numerals:

I. Bala SV, Samuelson K, Hagell P, Svensson B, Fridlund B, Hesselgard K (2012). The experience of care at nurse-led rheumatology clinics. Musculoskeletal Care 10, 202-211.

II. Bala SV, Samuelson K, Hagell P, Fridlund B, Forslind K, Svensson B, Thomé B (2016). Living with persistent rheumatoid arthritis. Journal of Clinical Nursing, doi: 10.1111/ jocn.13691.

III. Bala SV, Forslind K, Fridlund B, Samuelson K, Svensson B, Hagell P. Towards measurement of person-centered care in nurse-led outpatient rheumatology clinics. Submitted for publication.

IV. Bala SV, Forslind K, Fridlund B, Hagell P. Measuring person-centered care in nurse-led outpatient rheumatology clinics. Submitted for publication.

Permission has been obtained from each respective publisher to reprint the papers in their entirety in the dissertation.

Preface

During my many years of experience in the healthcare system, as a nurse and a leader, I have always valued the importance of the relationship between the patient perspective and the perspective of the healthcare organization, and have taken it into consideration in my work. I am convinced that good quality care can only be achieved by working together with patients, and that healthcare organizations can promote this opportunity on the one hand but also limit it on the other.

Following my contribution to implementing a nurse-led approach in outpatient rheumatology care at Helsingborg Hospital in Sweden in the early 2000s, I recognized that the issue of evaluation of the assumed benefits needed to be addressed. Rheumatology, for example, had moved into an expansive development phase, and there was broad interest in replicating this model at a national level. However, the lack of measurement instruments was clear, and the holistic nature of rheumatology nursing made it more difficult to find an appropriate one.

I therefore began to seek a way of transforming the words used by patients to show their appreciation or dissatisfaction into an understanding which could be quantified to enable comparison. At this point, I had yet to formulate concrete ideas, but I was very clear about two aspects: my aim was to find a way of measuring the outcomes of nurse-led clinics, and the best way to do this was to work closely with patients. Since then this has been taken to another level, culminating in this thesis.

The research for my thesis aimed to improve understanding of patients' experiences as a means of enabling measurement and further development of person-centered care and practice in nurse-led outpatient rheumatology clinics. It combined qualitative and quantitative research methods, using both inductive and deductive methodology. The new knowledge is a result of many years of clinical experience as a registered nurse, as well as experience in research and teaching in the field of rheumatology nursing. The complexity of the research project gave rise to a number of challenges, particularly as I was conducting it alongside my clinical work and leadership duties.

At the same time, it has been a privilege to do this research for several reasons. Firstly, the research topic, person-centered care, represents values which are very much in agreement with my own view of human beings. For me, a patient is a unique person, and also a partner who is an expert on her/his illness, as s/he is living with it. Through thought, action and attitude, I have always adopted a humanistic perspective based on respect, dignity and empathy with patients. Their voice and wellbeing have been very important to me throughout my professional years, and I have always sought to meet their needs and solve problems with respect for the person as a whole.

Secondly, I believe in and am very motivated to support developments in rheumatology care which originate in an ethical and moral ideal of solidarity, loyalty and engagement. By considering knowledge a question of lifelong learning, I have always sought value and truth as a way of giving more to patients and the nursing profession. I consider that both subjective and objective realities are valuable, as well as concrete and abstract levels of knowledge.

Lastly, the joy of having the opportunity to collaborate with and work with reputable researchers in nursing and medicine, well-versed in the care of people with chronic conditions and research methodologies, has been a truly unforgettable experience. Their contribution to this work and my personal development as a researcher is invaluable, and no words can express my gratitude for their outstanding efforts. During our many years of collaboration, I have appreciated our discussions and reflections on a variety of topics, and learned a lot from them. In particular, they improved my ability to manage the research phenomena in the different phases of the project.

My hope is that my thesis will bring value and new insights to all its readers, and that it will lead the way to further development and research in this area.

Helsingborg, July 2017

Valentina Bala

Introduction

Person-centered care (PCC) is considered a valuable approach for improving quality of care, clinical health outcomes and patient experience (WHO, 2015; Coulter et al., 2015; Harding et al., 2015; de Silva, 2014). PCC is rooted in a holistic paradigm, which brings the individual's perspective into focus and ensures that healthcare is built on the needs and preferences of the persons using it (WHO, 2015; Harding et al., 2015; Ekman et al., 2011). PCC has undergone considerable progress in many areas of care but is still underdeveloped in outpatient care. The complexity of the concept and lack of conceptual clarity (Kogan et al., 2016) have been identified as contributory factors to this situation, along with a lack of robust measurement (de Silva, 2014).

In the field of rheumatology, PCC is considered an unmet need (Winthrop et al., 2016), and further development is desired in person-centered practice and evaluation of this approach to care. In rheumatoid arthritis (RA), new care models have been required in the last few decades as a consequence of significant therapeutic developments (Smolen et al., 2016; Winthrop et al., 2016), increased accessibility requirements (Combe et al., 2017; Smolen et al., 2014, 2016), a lack of rheumatologists (Primdahl et al., 2014; Qian et al., 2010) and a shift from inpatient to outpatient care, resulting in an increased workload in the latter (Klareskog et al., 2000). Nurse-led care (NLC) is one such model, and has acquired an increasingly prominent role in the healthcare system for persons with chronic conditions. It is considered essential for the development of PCC (Nolte and McKee, 2008).

Although the contribution of NLC has been recognized in terms of improving patient outcomes in rheumatology (Garner et al., 2017; van Eijk-Hustings et al., 2012; Ndosi et al., 2011), its connection to PCC is less well understood. The availability of an instrument for measuring the degree of perceived PCC from the patient's perspective in nurse-led outpatient rheumatology clinics could circumvent this situation and enable person-centered outcomes to be monitored. In addition, it could help identify the need for improvements. The latter can arguably be considered the most important goal from a quality-assurance perspective. Conceptualizing and operationalizing outpatient PCC is therefore a high priority if a measurement instrument is to be devised to develop understanding of the benefits of this approach for persons with RA, and to develop outpatient rheumatology NLC further.

Perspectives of the thesis

The point of departure for this thesis is *the perspective of patients with RA as persons* who are both participants in, and beneficiaries of NLC. They are the most reliable source in terms of understanding unique lived experience and providing information about studied phenomena. The patient perspective is a key determinant of the content and organization of care, as well as its quality (van Eijk-Hustings et al., 2013).

Taking a naturalistic approach which emphasizes the importance of multiple and subjective realities (Polit and Beck, 2016), the patient perspective is captured by qualitative research methods. It is then used to develop hypotheses and conceptualize PCC in terms of developing a new instrument of measurement. A positivistic approach, which emphasizes reality as objective and generalizable (Polit and Beck, 2016), is then applied by quantitative research methods for testing the new instrument's measurement properties, and is alternated with deductive reasoning.

Another central perspective for this thesis is the *nursing perspective* in the context of outpatient rheumatology clinics, which focuses on the care meeting between the person with RA and the nurse. Optimal nursing is based on a holistic approach and founded on a patient perspective (Jacobi et al., 2004; Larrabee and Bolden, 2001). If outpatient NLC is to be improved for patients with RA, and adapted to suit the person's needs and preferences, it is essential to understand what really matters for the persons in terms of care in this specific context, and to ensure that the outcomes that matter most for them are taken into consideration (Kirwan et al., 2017). Furthermore, in terms of developing new outcome measures, integrating the perspectives of the patients as the persons who live with the disease is considered a prerequisite for identifying relevant and measurable person-centered outcomes (de Silva, 2014). This is also considered essential for enabling evaluation of care from a *person-centered perspective*, which is the ultimate goal of this thesis.

Background

Person-centered care (PCC): a shift in perspective

There has been a major focus on PCC in the healthcare system in the last decades. PCC is highlighted as a key component in the effective management of illness (Kogan et al., 2016; Cloninger, 2013; WHO, 2015), high quality care and improved outcomes (Harding et al., 2015; Olsson et al., 2013; Coulter and Collins, 2011; Mead and Bower, 2000). The point of departure for PCC is the person behind the patient, and her/his individual perspectives, needs, values, expectations, abilities and capacities (WHO, 2015; Ekman et al., 2011). PCC implies that healthcare professionals (HCPs) use the perspective and attributes of person-centeredness for developing and maintaining relationships, as well as for planning and delivering care (Slater, 2006). PCC represents a shift away from production of care to co-production of care, from the traditional biomedical model in which the patient is the passive target of medical interventions to a more human and value-based model, which involves the patient as an active part in her/his care and in the decision-making process (McCormack et al., 2015; Miles, 2012; Ekman et al., 2011; Leplege et al., 2007). The International College of Person-Centered Medicine described PCC as “a medicine of the person, for the person, by the person and with the person” (Casell, 2010). In contrast to patient-centered care, which is more disease-focused, PCC is based on accumulated knowledge of the person, and is in a better position to recognize health problems and needs over time (Starfield, 2011): “the disease is part of the person and not the person part of the disease” (Miles, 2012).

PCC and person-centeredness from theoretical standpoints

The World Health Organization (WHO) has promoted PCC by establishing a set of core principles, which include attributes such as tailored, holistic, collaborative, ethical, empowering and co-produced (WHO, 2015). The Health Foundation suggested four key principles which underpin PCC, stating that the person should be (i) treated with dignity, compassion and respect, and offered (ii) personalized, (iii) coordinated and (iv) enabling care (Collins, 2014). Similarly, person-centeredness is advocated as an approach to practice which encompasses principles of respect for persons, their human rights, values and beliefs, and the development of therapeutic relationships based on mutual respect and understanding (McCormack et al., 2015). Thus, these similarities reinforce an obvious inherent synergy between PCC and person-centeredness. In both, "the person" is central, and person-centeredness is a significant focus for PCC as it confirms the importance of human and ethical rights of the persons and the importance of relationships and holistic care in maintaining wellbeing (Slater, 2006).

To enable nurses to explore PCC systematically and ensure person-centeredness in their practice, McCormack and McCance (2006) developed the person-centered nursing framework, consisting of four components: prerequisites (the attributes of the nurse); the care environment (the context in which care is delivered); person-centered processes (the range of activities used for delivering care) and expected outcomes (the results of person-centered nursing). This framework has been proposed as a tool to help identify key dimensions in nursing practice and for operationalizing PCC (McCance et al., 2011). Furthermore, to facilitate transition to, and implementation of PCC, Ekman et al. (2011) developed the Gothenburg PCC model. This establishes three routines for co-creation of care: (i) initiating the partnership: patient narratives; (ii) working the partnership: shared decision-making; (iii) safeguarding the partnership: documenting the narrative.

Person-centeredness and PCC are now considered "a global movement" (McCormack et al., 2015) toward models of care which adopt an individual perspective, and which prioritize co-production of health by organizing care around individuals' needs and expectations rather than diseases (WHO, 2015). On the other hand, challenges in defining the concept have presented barriers in terms of measuring PCC and incorporating it into routine clinical practice, particularly in outpatient care (Kogan et al., 2016; Harding et al., 2015; de Silva, 2014).

Measuring PCC outcomes in outpatient care

PCC is widely advocated as a desirable approach in terms of personalizing care (Olsson et al., 2013). Thus, introducing PCC into clinical practice is a priority, but this also implies a commitment to measuring person-centered outcomes (Harding et al., 2015; Collins, 2014; McCormack and McCance, 2006).

Phenomena like PCC, which cannot be directly observed, are considered latent variables, and measuring them relies on observable expressions and manifestations that operationalize variations in the latent variable (Hagell, 2014). Measuring PCC can therefore be seen as a critical test related to the complexity of the concept, particularly in view of the lack of an agreed definition (Kogan et al., 2016).

Available PCC instruments generally apply to inpatient and long-term residential contexts and concern assessments made by staff (de Silva, 2014). However, instruments have also been proposed for evaluating PCC from a patient perspective (Harding et al., 2015; de Silva, 2014; Edvardsson et al., 2009; Suhonen et al., 2005; Coyle and Williams, 2001). A common approach in existing instruments has involved operationalizing PCC on the basis of its components, and communication, shared decision-making, co-production and self-management are some of the most commonly operationalized aspects of PCC (Harding et al., 2015).

Using measures which can provide insights into practice is important in demonstrating the effectiveness of PCC, and particularly in identifying the need for improvement, such as individuals and contexts that would most benefit from a greater degree of PCC (McCance et al., 2009). However, in spite of efforts to develop valid and reliable measures, progress in developing measurement for PCC has been a challenge due to a lack of consensus on what PCC means (Harding et al., 2015; de Silva, 2014). This is particularly evident in the context of outpatient care and in terms of measuring PCC from the perspective of persons living with long-term conditions (Kogan et al., 2016; de Silva, 2014).

Rheumatoid arthritis (RA)

Rheumatoid arthritis (RA) is a chronic, autoimmune and progressive inflammatory disease causing pain, fatigue, stiffness, swollen and damaged joints, and reduced quality of life (Klareskog et al., 2009; Smolen and Aletaha, 2009; Harris and Firestein, 2009). The prevalence of RA in the adult population in Sweden is about 0.70% (Neovius et al., 2011). The mean (SD) age of onset for women is 54 (14) years and for men 58 (13) years. Women are afflicted two to three times more often than men (Harris and Firestein, 2009).

RA is characterized by a fluctuating course, with unpredictable periods of relapse (Daker-White et al., 2014). The greater the level of inflammation, the more active the illness, with a greater effect on the individual's physical, psychological and social status (Young et al., 2000; Daker-White et al., 2014; Poh et al., 2017). The care of patients with RA seeks to alleviate symptoms, prevent joint destruction, and maintain physical and psychosocial functional capacity and the ability to work (Turkiewicz and Moreland, 2006). RA is usually managed by multidisciplinary teams using several approaches: medication, regular monitoring, patient education, physiotherapy, self-management and continuous support (Ndosi et al., 2011). A good prognosis depends on diagnosis at an early stage of the disease, so that appropriate treatment can be started before irreversible joint destruction has developed (Smolen and Aletaha, 2009).

Living with RA can dramatically transform the self (Iaquinta and Larrabee, 2004), and lived experiences include pain, negative feelings, a need for support from family and others (Hwang et al., 2004) and a need for work interventions (Codd et al., 2010). For example, RA affects identity in private life, and in public roles and responsibilities (Lempp et al., 2006). The unpredictable nature of RA can lead to feelings of being redefined by the illness (Dubouloz et al., 2004) and seeking a transition into new ways of living meaningfully with the disease (Neill, 2002). Supportive, timely guidance is needed to handle periods of uncertainty and to develop strategies for coping with the changes caused by the disease (Shaul, 1995). Moreover, while environmental facilitators can improve the level to which a person functions, barriers in physical environments, loss of a sense of self and independence, low income and sparse basic services can exacerbate negative experiences of living with RA (Schneider et al., 2008).

The ultimate aim in treating patients with RA is remission (Smolen et al., 2010), i.e. being clinically free from signs of active illness and disease activity. From a patient perspective, remission also means a decrease in the daily impact of their condition and the feeling of a return to normality (van Tuyl et al., 2015).

A dramatic development has taken place in the pharmacological treatment of RA in the last decades, and the use of biological drugs has led to significantly improved outcomes (Smolen et al., 2014) and prognoses (Du Pan et al., 2012). However, for a considerable number of patients living with RA, the disease remains active and continues to cause symptoms despite the availability of potent anti-rheumatic treatment (Du Pan et al., 2012; Emery, 2014; Svensson et al., 2016). For example, long-term follow-up of participants in the Better Anti-Rheumatic PharmacoTherapy (BARFOT) study showed that about one-third of the patients had persistent disease activity for several years following diagnosis, which was more common among women and among those who did not experience remission during the first six months (Svensson et al., 2016).

Clinical assessments

A wide range of tools is available for clinical assessment of various aspects of RA. In this thesis, disease activity is reported by using the composite index Disease Activity Score calculated on 28 joints (DAS28) (Prevoo et al., 1995), and limitations on activities in daily life are assessed by means of the Health Assessment Questionnaire (HAQ) (Fries et al., 1980; Ekdahl et al., 1988).

The DAS28 includes number of swollen joints (SJC28), number of tender joints (TJC28), patient's global assessment of disease activity (PatGA) measured on a visual analogue scale (VAS, range 0-100 mm, 100=worse) and erythrocyte sedimentation rate (ESR, mm/h). Scores >5.1 imply high disease activity, scores ≤5.1 - >3.2 moderate disease activity, scores ≤3.2 - ≥2.6 low disease activity and scores <2.6 suggest remission (Prevoo et al., 1996). Persistent RA has been defined as DAS28 scores >2.6 at all predefined follow-up visits after the first 6 months of the disease (Svensson et al., 2016).

The HAQ is a 20-item patient-reported rating scale covering eight areas of daily activity. Each item is scored according to a 4-point scale (0-3), and the highest scores from each area are summed and divided by eight to derive a total HAQ score, which can range from 0 to 3 (3=worse). A total HAQ cut-off score at <1 vs. ≥1.0 has been suggested to define clinically relevant levels of disability (Thyberg et al., 2012).

PCC in outpatient rheumatology care

There has been considerable progress in PCC in many areas such as elderly, dementia, palliative and primary care, whereas it is considerably less developed in other areas (Kogan et al., 2016; Harding et al., 2015). There is currently a gap in, and a need for means for assessing PCC practice in outpatient contexts. For example, PCC and co-management of chronic rheumatic diseases have been identified as unmet needs in rheumatology care (Winthrop et al., 2016). As mentioned above, despite recent advances, more than a third of persons with RA still have an ongoing active and symptomatic disease (Svensson et al., 2016; Cook et al., 2016). There is therefore more work to be done to help patients living with severe RA disease. It has been argued that there is a need for alternatives to conventional clinical practice, and for more collaborative models in which patients can decide to a greater degree which services they need and how these services should be delivered (Kjeken et al., 2006). In addition, evaluation of PCC will be essential to develop person-centered practice in outpatient rheumatology care.

Nurse-led care (NLC) in outpatient rheumatology clinics

Dr. Jackie Hill from the UK, who has made a major contribution to the current body of knowledge and evidence on nurse-led arthritis clinics, first described these clinics as parallel to rheumatologist clinics, providing follow-up care, patient education, advice and support (Hill, 1985). The clinics were also described as giving nurses the opportunity to adopt a structured and continuous approach to care which patients wanted and appreciated (Hill, 2006; Hill and Pollard, 2004; Hill, 1985).

More recently, NLC in outpatient rheumatology clinics has been defined as a practice in which nurses provide advanced and independent patient care involving interventions such as caring, helping, supporting, educating and counseling. It also involves coordinating care, monitoring the course of the disease, treatment and wellbeing, and collaborating with physicians and other healthcare professionals (HCPs) (Garner et al., 2017; Ndosi et al., 2011). Thus, NLC in outpatient rheumatology clinics allows nurses to undertake extended roles and adopt a holistic, person-centered approach to the delivery of care (Garner et al., 2017; Larsson et al., 2012; van Eijk-Hustings et al., 2012; Ryan et al., 2006; Arvidsson et al., 2006).

During the last decades, a nurse-led approach has been applied increasingly, and nowadays nurse-led arthritis clinics are established in many countries (van Eijk-Hustings et al., 2012). Their effectiveness, safety and cost-effectiveness have been documented, as has their added value in contributing to improved patient outcomes (Garner et al., 2017; Larsson et al., 2014; Ndosi et al., 2011; Ryan et al., 2006; Hill et al., 2003; Hill et al., 1994).

The European League Against Rheumatism (EULAR) has formulated ten recommendations for the role of nurses in the care and management of chronic inflammatory arthritis, and according to these the role follows a worldwide movement towards more proactive, evidence-based care with an extended nursing role (van Eijk-Hustings et al., 2012). The recommendations and the development of nurse-led clinics have gradually helped define NLC more clearly and incorporate it increasingly into the care of persons with RA. However, there is still a need for more systematic and consistent NLC practice, with further development and quality assurance to ensure high-quality care (Garner et al., 2017).

Aspects of outpatient NLC experienced as essential by persons with RA

Because it takes account of individuals' needs, their unique experiences, perspectives, values and expectations (Ndosi et al., 2013; van Eijk-Hustings et al., 2013; Ryan et al., 2006), the PCC approach has been identified as a success factor for NLC (Garner et al., 2017).

By using qualitative research methods have been found that persons with RA emphasize the importance of nurses' competence, skills and professionalism in meeting their needs in terms of security, accessibility, continuity, trust, hope, confidence, familiarity and participation (Larsson et al., 2012; Primdahl et al., 2011; Ryan et al., 2006a; Arvidsson et al., 2006; Hill, 1986). Nurses' skills in personalizing care, identifying abilities and involving patients in decisions about their health are considered pivotal in the quality of the care patients perceive (Larsson et al., 2012). By using persons' narratives on their illness as a starting point for dialogue and partnership, nurses can involve patients in taking an active role in their treatment and care planning, in order to identify solutions and solve their problems (Larsson et al., 2014; Arvidsson et al., 2006). Persons with RA expect to be listened to and understood, to be given attention and contact for sufficient periods of time, to receive appropriate, tailored and timely information, advice and supportive communication, and to share their health problems with HCPs in addition to the support received from relatives and friends (van Eijk-Hustings et al., 2013; Ryan et al., 2013; Primdahl et al., 2011). Furthermore, well-organized and coordinated care is expected, with good collaboration and communication between nurses and other HCPs (van Eijk-Hustings et al., 2013), and persons with RA consider a good caring environment a strengthening factor (Larsson et al., 2009). A relationship based on empathy, mutual respect and dignity, where the nurse confirms the person and establishes equality in the meeting, is considered a key factor in a good partnership between patients and nurses (van Eijk-Hustings et al., 2013; Arthur and Clifford, 2004). Communication, verbal as well as non-verbal, appears to be one of the most important aspects of care, with major implications for the whole care process and how it is experienced (Ryan et al., 2013).

Rationale of the thesis

In recent decades, RA care has undergone significant developments, but also challenges. Therefore, new care models have been required, of which NLC is one that is considered effective, acceptable, and safe. By taking into account the individuals' needs, their unique experiences, perspectives, values and expectations, NLC is in an excellent position to promote and deliver PCC. However, lack of agreement about what PCC means in outpatient NLC for persons with RA and absence of means to evaluate clinical practice from a person-centered perspective represent barriers for further development and quality assurance of NLC. It is therefore a high priority to conceptualize PCC within outpatient rheumatology NLC by identifying and using aspects of care that really matter to persons with RA in relation to person-centeredness and existing PCC frameworks, and to operationalize the resulting PCC framework into a measurement instrument. This work sought to begin filling this gap in order to better understand the benefits of and further develop outpatient NLC in rheumatology clinics for patients with RA.

Aim of the thesis

The overall aim of this thesis was to describe and understand patients' experiences as a means to conceptualize and evaluate outpatient PCC in nurse-led clinics for patients with RA.

Specific aims

- To describe how people with RA experience the care provided by Swedish nurse-led rheumatology outpatient clinics (Paper I).
- To describe and understand the meaning of living with persistent RA (Paper II).
- To conceptualize and operationalize PCC in order to develop an instrument for measuring patient perceived PCC in nurse-led outpatient rheumatology clinics (Paper III).
- To test the extent to which the PCCoc/rheum represents the underpinning conceptual outpatient framework, and to test its measurement properties as applied in nurse-led outpatient rheumatology clinics (Paper IV).

The only source of knowledge is experience.

Albert Einstein

Methods

This thesis uses a multi-method design which combines qualitative and quantitative methodologies. The starting point for the thesis is an inductive phase using qualitative research methods which provide a patient perspective (Papers I-II). This is followed by a deductive phase which adopts a hypothetical deductive approach (Paper III, Stage I), and uses quantitative research methods (Paper III, Stage II; Paper IV) and psychometric hypothesis testing (Paper IV). An overview of the studies is presented in Table 1 and their mutual relationship in Figure 1.

Table 1.
Overview of the design, participants, data collection and analysis in the thesis

	Inductive Phase		**Deductive Phase**	
	Paper I	Paper II	Paper III	Paper IV
Design	Descriptive, qualitative method	Phenomenological, qualitative method	Hypothetical deductive approach (Stage I) Quantitative method (Stage II)	Quantitative method Psychometric hypothesis testing Multicenter, cross-sectional
Participants (n)	Patients with RA (n=18)	Patients with persistent RA (n=10)	Stage I: Research team and expert-group (n=6) Stage II: Patients with RA (n=50)	Patients with RA (n=316)
Data collection	Semi-structured interviews	Open-ended interviews	Stage I: Empirical and theoretical data II. Structured interviews and questionnaire booklet	Questionnaire booklet
Data analyses	Qualitative content analysis	Hermeneutic phenomenological analysis	Stage I: Theoretical logical reasoning Stage II: Descriptive statistics and content validity	Descriptive statistics Rasch measurement theory

RA, rheumatoid arthritis.

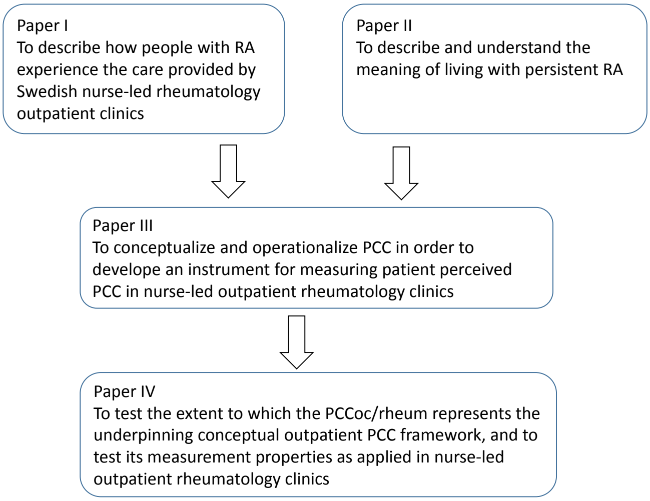

Figure 1.
An overview of the studies and their mutual relationships in the thesis. RA, rheumatoid arthritis; PCC, person-centered care; PCCoc/rheum, the Person-Centered Care instrument for outpatient care in rheumatology.

Inductive phase

This phase used empirical studies to capture the patient perspective by describing patients' experiences of care at nurse-led rheumatology clinics (Paper I) and among patients living with severe, persistent RA (Paper II). According to Taylor and Bogdan (1998), qualitative research methods are an appropriate choice if the researcher has a holistic interest in people and settings.

Design and settings

Paper I

The study had a descriptive, explorative design with a qualitative approach inspired by thematic content analysis (Burnard, 1991). It was carried out at three Swedish nurse-led rheumatology outpatient clinics over two months. All nurse-led clinics offered individual patient visits, day-care visits, telephone helplines and patient education in groups, as detailed in Table 2.

Paper II

The study was carried out at three Swedish rheumatology outpatient clinics during a period of nine months, and applied the hermeneutic phenomenological method described by van Manen (1990, 2001). The clinics participated in the long-term follow-up BARFOT study which has been ongoing since 1992 (Svensson et al., 2003).

Table 2.
Examples of nursing interventions at the three nurse-led rheumatology outpatient clinics

Individual patient visits
Initiation and monitoring of drug therapies
Monitoring of disease course, medication and wellbeing
Patient education and support
Assessment of disease activity (DAS28)
Day-care visits
Administration of infusions, including pre- and postinfusion monitoring
Telephone helpline
Daily availability during certain hours
Possibility to book time for phone calls
Patient education in groups
Coordination of multidisciplinary patient education programs

DAS28, Disease Activity Score calculated on 28 joints.

Participants

Paper I

Eligible participants were adults with RA, who had at least three documented contacts with the nurse-led clinics, of which at least one was a visit. A strategic sample was employed to maximize variation in terms of age, gender and disease duration. Four nurses who were specialized in rheumatology recruited participants. Eighteen people (17 women) were recruited (aged 41-72 years; disease duration: 1-58 years).

Paper II

Adult patients were eligible if they had persistent RA with a disease duration of ≥5 years despite ongoing anti-rheumatic treatment. A strategic sampling procedure was used to maximize variation in terms of gender, disease duration and outpatient clinic. The patients were selected from the BARFOT register by their attending physicians or nurses. Ten patients agreed to participate (5 women; aged 56-78 years; disease duration: 6-20 years).

Data collection

Data were collected using qualitative semi-structured interviews (Paper I) and qualitative open-ended interviews (Paper II). A qualitative research interview is a dialogue between two parties on a topic of mutual interest (Kvale, 1997). The interviewer (SVB) thus sought to establish a trusting contact with the participants and a reflective approach to the studied phenomenon.

Pre-understanding

Researchers are often both instruments for data collection and the people who conduct the analysis. The question of researchers' qualifications, skills and experience is therefore important and has significance for their credibility in a qualitative research study (Patton, 2004). Consequently, it is important that researchers are conscious of their pre-understanding and take preventive action to minimize its influence on the data collection and analysis (van Manen, 1997). The author of this thesis is a registered nurse. Her pre-understanding is based on many years of clinical experience as a rheumatology nurse and teaching in the field of rheumatology nursing. The co-authors were either nurses (KH, BT, KS, PH and BF) or rheumatologists (KF and BS), well-versed in the care of people with chronic conditions, and/or in qualitative research methods (KH, BT, KS and BF). Prior to, and during the studies, the author and co-authors discussed and reflected on their own pre-understanding and its importance for the research process, making it explicit and then attempting to bracket it.

Paper I

Participants were interviewed at the location of their choice, 15 at the clinics and three in participants' homes. The interviews lasted for an average of 40 minutes, and were recorded and transcribed verbatim. The interviews began with an open-ended question: "Can you describe how you experience the care you receive at the nurse-led clinic?" and continued with three more detailed questions: "Can you tell me what you experienced as positive with the care and what happened in that situation/ those situations?", "Can you tell me what you experienced as less positive with the care and what happened in that situation/ those situations?" and "Can you tell me what you feel when you are taken care of at the nurse-led clinic?". When necessary, follow-up questions or prompts such as: "Can you give more details?", "What do you mean?" or "Please continue" were used.

Paper II

Half of the interviews (n=5) were conducted at the clinic, and half in participants' homes. The initial open question was: "Can you tell me what it is like to live with rheumatoid arthritis?" Probing questions such as "What do you mean?" or "Please tell me more" were used where necessary. The interviews lasted an average of 90 minutes, and were recorded and transcribed verbatim, together with notes taken during the interviews.

Qualitative data analyses

Qualitative content analysis (Paper I)

Data were analyzed using a descriptive, explorative approach inspired by thematic content analysis (Burnard, 1991). This entails a detailed and systematic analysis of the themes which have emerged from the semi-structured interviews in order to link them in a category system (Burnard, 1991). Data were analyzed stepwise (steps 1-10, 12-14) in accordance with Burnard (1991). Step 11 (checking results with participants) was not performed, as participants had additional experiences in the interim that could have affected the results. Units of significant meaning were identified, condensed and coded. The codes were then grouped into sub-categories which, in turn, were abstracted into categories. Two authors (SVB, KH) examined the categories critically and independently, followed by discussions until consensus was reached (Burnard, 1991).

Hermeneutic phenomenological analysis (Paper II)

This study applied the hermeneutic phenomenological method as described by van Manen (1990, 2001). It begins in the lifeworld, i.e. the natural attitude of everyday life (van Manen, 1997), and combines interpretive (hermeneutic) and descriptive (phenomenological) elements. The aim is to describe lived experiences, their meaning and variations, and to discover what is unique about a phenomenon and what its nature or essence is (van Manen, 2001), i.e. here "living with persistent RA". First, in what is known as a "holistic reading approach" (van Manen, 1997), each interview was read repeatedly to capture its fundamental meaning. The ways in which the lived experiences of the phenomenon appeared in each interview were recorded as essential themes. To verify each theme, the text was reviewed using a "selective reading approach" (van Manen, 1997), which entailed identifying expressions of the theme. The essential themes and their variations were then discussed by the authors, and unique, overall essential themes were identified. Hermeneutic phenomenology seeks to create text that is reflective and rich in meaning, and the researcher is seen as an active co-creator in the process of analyzing and writing (van Manen, 2006)

Trustworthiness in the qualitative research process

Trustworthiness was taken into account throughout the research process in terms of the follows aspects:

Credibility refers to confidence in the accuracy of data, articulating that the research is conducted in such a way that the credibility of the result is enhanced (Lincoln & Guba, 1985). To strengthen credibility, the participants were selected from several rheumatology clinics according to defined inclusion criteria, to maximize the variation and richness in participants' experiences. An optimal variation was sought in the selection, and a large number of complex descriptions were obtained of the experiences of care and living with persistent RA. The findings are illustrated by citations and explanations of the procedures from transcripts to categories and themes.

Transferability means that the findings can be applied to other, similar contexts depending on the degree of similarity between the contexts themselves (Lincoln & Guba, 1985). The care contexts and participants were thus described carefully, and findings should be of value to similar nurse-led rheumatology outpatient clinics and patients.

Dependability refers to the stability of data. The criterion for dependability is difficult to establish in qualitative research, and a good description of the credibility is therefore considered sufficient to establish dependability (Lincoln and Guba, 1985). To strengthen dependability, two to three authors conducted the data analysis separately and then compared and discussed the results. Then the other co-authors joined the discussion.

Confirmability refers to the steps taken to demonstrate that the findings genuinely emerged from the data and were not influenced by the bias, interests or perspectives of the researcher (Lincoln and Guba, 1985). To strengthen confirmability, all interviews were carried out by the same person in an undisturbed environment that felt comfortable for the participants. The interviewer was a nurse by profession, which may have influenced the interview situation, but she was never involved in the care of the participants and reflected on her pre-understanding, both personally and within the research group. In addition, the findings were consistently illustrated by citations.

Deductive phase

This phase began with theoretical, logical reasoning using empirical and theoretical data to conceptualize a PCC framework for nurse-led outpatient rheumatology clinics (Paper III, Stage I). The underlying theoretical issue for this approach was:

PCC needs to be conceptualized for a better understanding of the aspects of care persons with RA experience as essential, and for relating these aspects to existing principles and frameworks of PCC and person-centeredness.

Following development of the conceptual framework, two hypotheses emerged and were tested in the development of a new measurement instrument:

Hypothesis I (Paper III)

The resulting conceptual framework for outpatient PCC can be operationalized into an instrument for measurement through descriptors (items) of aspects of care which can be applied to the unique person with RA.

Hypothesis II (Paper III-IV)

The measurement instrument represents the hypothesized PCC framework and can be used as an instrument for measurement of PCC at nurse-led rheumatology clinics.

Conceptual framework and initial instrument development

Paper III, Stage 1

The process of this stage took into account the perspective of patients with different levels of disease burden (from patients in remission to patients with severe, persistent RA) as described in available interview data (Papers I and II), as well as experiences described in other rheumatology nursing research (Larsson et al., 2014; Larsson et al., 2012; van Eijk-Hustings et al., 2013; van Eijk-Hustings et al., 2012; Ryan et al., 2013; Ryan et al., 2006a; Primdahl et al., 2010; Arvidsson et al., 2006; Arthur and Clifford, 2004; Hill, 1986). In addition, the principles of PCC (WHO, 2015) and person-centeredness (McCormack et al., 2004; 2015), the person-centered nursing framework (McCormack and McCance, 2006), the co-creation of care according to the Gothenburg PCC model (Ekman et al., 2011) and existing PCC instruments from other contexts (Edvardsson et al., 2009; Suhonen et al., 2005; Coyle and Williams, 2001) were considered.

The conceptual work was undertaken to develop a PCC framework for the outpatient context, focusing on the meeting between the person with RA and the nurse, and on the patient as an active partner in the care process. To operationalize this PCC framework into a measurement instrument, a pool of items was generated. According to Wolfe and Smith (2007), it is recommended to create a fairly large list of items to sample from. In this process a “bottom-up approach" (Wolfe and Smith, 2007; Enos, 2008; Wilson, 2005) was used to describe the latent PCC variable, its variations and expressions from lower to higher levels of perceived outpatient PCC, and for developing items (statements) that operationalize these variations. Six experts (two persons with RA, two rheumatology nurses and two rheumatologists) reviewed the item pool in terms of wording. Items were then conceptually mapped along a theoretical continuum from lower to higher levels of PCC. In other words, a lower-level item represented something which could be achieved without a very large degree PCC input, and vice versa for higher-level items. Four and two response categories (levels of agreement) were considered. The resulting preliminary PCC instrument for outpatient care in rheumatology (PCCoc/rheum) was then subjected to further testing.

Settings and participants

Evaluation of items and response categories (Paper III, Stage 2)

Fifty persons with RA (Table 3) attending a southern Swedish nurse-led clinic were recruited consecutively by four nurses in connection with visits to the clinic.

Testing the measurement properties (Paper IV)

The study was a multicenter, cross-sectional survey involving six southern Swedish nurse-led outpatient rheumatology clinics in the BARFOT-cohort (Svensson et al., 2003). Eligible participants were adults with RA, and at least three documented nurse-led clinics contacts (at least two clinic visits); 343 persons were included of which 316 (58 with persistent disease) answered the PCCoc/rheum (Table 3).

Table 3.
Participant characteristics in the development and testing of the PCCoc/rheum

	Paper III		**Paper IV**
Characteristics	32-item PCCoc/rheum	35-item PCCoc/rheum	24-/21-item PCCoc/rheum
n	20	30	316
Age (years), mean (SD)	64.2 (13.3)	55.4 (16.7)	63.1 (12.7)
Female, n (%)	12(60)	24(80)	244 (77)
Disease duration (years), mean (SD)	15.5 (10.3)	9.9 (8.4)	14.8 (9.9)
Marital status, n (%)			
Cohabiting	11 (55)	19 (63)	234(74)
Living alone	9 (45)	11 (37)	80 (25)
Educational level, n (%)			
Comprehensive school	4 (20)	12 (40)	113 (35.8)
Upper secondary school	11(55)	11 (37)	117 (37)
University	5 (25)	7 (23)	84 (26.6)
Contact with nurse-led clinic (years), mean (SD)	6.4 (4.9)	6.3 (4.5)	9.1 (6.2)
Persistent RA, n (%)	5 (25)	7 (23)	
DAS28 score, mean (SD) [a]	-	-	3.3 (1.4)
HAQ score, mean (SD)	-	-	0.78 (0.6)

[a] Within the last six months (n=167).
PCCoc/rheum, the Person-Centered Care instrument for outpatient care in rheumatology; RA, rheumatoid arthritis; DAS28, Disease Activity Score calculated on 28 joints; HAQ, Health Assessment Questionnaire.

Data collection

Evaluation of items and response categories (Paper III, Stage 2)

Participants completed the preliminary PCCoc/rheum instrument along with demographic questions, and were then interviewed according to a structured interview guide. All interviews were conducted by the author (SVB), who was not involved in the participants’ care.

All participants answered the PCCoc/rheum independently. The interviewer was present in the first 30 cases in order to note difficulties and record the time taken to complete the PCCoc/rheum. The first 20 participants answered both PCCoc/rheum versions (with four and two response categories) in random order. Participants were then asked to comment on the instructions, items and response categories, and to consider the acceptability, clarity, comprehensiveness and relevance of the contents of each item. The results of these 20 interviews were used to review the questionnaire for potential revisions. The PCCoc/rheum was then completed by the remaining 30 participants. Ten of them performed the same evaluation as described above, as well as an evaluation of content validity. The last 20 participants only responded to the PCCoc/rheum (Appendix 1) and evaluated content validity.

Testing the measurement properties (Paper IV)

A questionnaire booklet, including the PCCoc/rheum, demographic and RA/health-related questions, and the Swedish HAQ (Ekdahl et al., 1988), was distributed by nurses in connection with visits to clinics. Patients were instructed to complete the questionnaires independently and then return the booklet to the author using a pre-stamped and addressed envelope. All participants were also invited to complete the PCCoc/rheum a second time to estimate test-retest stability. Those who consented were sent a second copy of the PCCoc/rheum 2 weeks later. In addition, nurses reported the most recent disease activity assessments according to the DAS28 (Prevoo et al., 1995).

Quantitative data analyses

Evaluation of items and response categories (Paper III, Stage 2)

Interview and demographic data were analyzed descriptively. Content validity was estimated by calculating the Content Validity Index (CVI). The CVI is a method of assessing content validity of individual items (I-CVI) and of the overall scale (S-CVI) (Lynn, 1986; Polit and Beck, 2006). Respondents were asked to indicate whether they considered the content of each item “not”, “somewhat”, “quite” or “highly” relevant. I-CVI is expressed as the proportion of respondents who consider each item “quite” or “highly” relevant, and S-CVI is calculated as the average I-CVI across items (Polit and Beck, 2006). I-CVI values ≥0.78 and a minimum S-CVI value of 0.90 were considered acceptable (Polit and Beck, 2006). All statistical analyses were performed using IBM SPSS version 22.

Testing the measurement properties (Paper IV)

Demographic and RA/health-related data were analyzed descriptively, and PCCoc/rheum test-retest stability was assessed by the intra-class correlation (2-way mixed model, single measure, absolute agreement) between total scores from time 1 and time 2 using IBM SPSS version 22.

The measurement properties of the PCCoc/rheum were tested according to Rasch measurement theory (RMT) (Rasch, 1960; Andrich, 1988; Hobart and Cano, 2009). In contrast to classical test theory, which is founded on correlational analyses, RMT builds on the same principles as those underpinning measurement in the physical sciences (Rasch, 1960; Andrich, 1988; Pendrill, 2014).

In RMT, the total score is a sufficient statistic, and the probability of a certain item response is a function of the difference between the levels of the measured construct (in this case, PCC), represented by the item and by the person, respectively. The locations (measures) of both persons and items are estimated on a common linear logit (log-odd units) metric, which can take values from minus to plus infinity (with mean item location set at zero), and represents a common "ruler". Preferably, persons and items should be located at approximately the same levels in order to maximize the precision of estimates.

The RMT analyses here focused on the following aspects:

- Targeting, i.e. the accord between item and person locations on the common logit scale.
- Reliability was estimated by the person separation index (PSI), which is conceptually analogous to coefficient alpha and should be ≥0.7.
- Model fit, as assessed by (i) item fit residuals that represent the difference between observed and expected responses, and are generally expected to range between −2.5 and +2.5, where large positive and negative values suggest multidimensionality and local response dependency, respectively; (ii) item chi-square statistics (should be non-significant); and (iii) item characteristic curves (ICC), which depict the accordance between model expectations and empirical item responses graphically.
- Differential Item Functioning (DIF), which is an additional aspect of model fit, was tested by age (defined by the median), sex, disease duration (defined by the median), HAQ-score (<1 vs. ≥1.0), disease activity (DAS28 <3.2 vs. ≥3.2), disease course (non-persistent vs. persistent RA) and time (time 1 vs. time 2).
- Response-category functioning, i.e. whether ordered response categories work as expected by representing increasing levels from less to more. This was assessed by the ordering of response-category thresholds (the locations on the measurement continuum at which the probability of responding to either of two adjacent categories is equal).
- The hierarchical item ordering was studied to assess the internal construct validity of the PCCoc/rheum. This is possible since RMT locates items along a linear continuum from less to more. The empirical item ordering was compared to expectations based on the underpinning theoretical PCC framework, with general agreement taken as support for the conceptual framework and its operationalization in the PCCoc/rheum.

For methodological details, see Andrich, 1988; Hobart and Cano, 2009; Andrich, 2013; Wright and Masters, 1982.

RMT analyses were conducted using the unrestricted polytomous Rasch model, with the sample divided into six class intervals using the RUMM2030 software (Andrich et al., 1997-2015). Due to the large number of tests, Bonferroni adjustments for multiple null hypothesis testing (Bland and Altman, 1995) were applied at a significance level of 0.05 (Hagell and Westergren, 2016).

Considerations involving sample size

In terms of quantitative analysis, traditional power calculation is not of major interest in this thesis because the purpose is to obtain stable results rather than statistical significance. About 10 well-selected experts are considered sufficient to evaluate the CVI (Lynn, 1986), and sample sizes of as few as 20 people have been found sufficient for stable estimates of test-retest stability (Hobart et al., 2012). In analyses according to RMT, sample sizes of n=250-500 have been found to represent a good balance between power and precision (Hagell and Westergren, 2016).

Ethical considerations

The studies in this thesis were conducted in accordance with the Declaration of Helsinki (2013), and were approved by the local Research Ethical Review Board of Lund University (Dnr. 2009/57: Paper I and Dnr. 2013/258: Papers II-IV). The ethical principles of autonomy, non-maleficence, beneficence and justice were considered in all four studies.

Autonomy

Eligible participants were informed about the studies by rheumatology nurses or physicians in outpatient clinics. The information given included the purpose of the specific study (I-IV), and the fact that participation was voluntary and consent could be withdrawn at any time without consequences for participants' continued care and treatment. Autonomy was also strengthened by the fact that the participants were not dependent on the author or other researchers involved in the studies. Participants who did not spontaneously consent to be interviewed were not subjected to any further pressure to participate, and those who did not respond to the questionnaire booklet were reminded only twice, after 2 and 5 weeks.

All participants provided oral and written informed consent before they were interviewed (Papers I -III) or answered the questionnaires (Papers III-IV).

Confidentiality was guaranteed for the entire research process, and was secured by coding all tape-recordings, transcribed interviews and completed questionnaires. Only the codes were used in the database (Papers III and IV). The lists of codes and names were kept in a safe, separated from the data.

Beneficence

The participants derived no direct benefit from participating in the studies, but several of them said it felt good to contribute to the development of rheumatology care by sharing their experiences. Some also noted that participation provided insights into how they could influence their care.

Non-maleficence

Following informed consent, the interviews took place at the location of the participants' choice, at the clinics or in their homes. All interviews were conducted by the author, who was prepared for the possibility that conversations could invoke thoughts and feelings in participants. In these cases, she indicated that she understood. She invited the participants to express these experiences, did not interrupt periods of silence and allowed them to decide how long they wished to continue with the interview. Suitable contacts in the healthcare services were arranged for participants who expressed a need for care during or in connection with the interview.

Interviews and questionnaires are well-established methods in the healthcare system, and are not usually harmful to participants. A potentially negative effect might have been that participants found the questionnaires or interviews a burden, or considered them to violate their integrity. However, the experience revealed that the participants found the type of questions highlighted in this thesis relevant and unproblematic.

Justice

The author applied for permission and received authority to obtain information about consenting participants from the BARFOT-register (Paper II). Participants who consented to answer the questionnaires (Papers IV) were asked for permission to retrieve relevant information from their medical records, and they gave this permission to the nurses at the clinics.

Results

The experience of care at nurse-led rheumatology clinics (Paper I)

The study identified three main categories, which described how the care offered by the nurse-led rheumatology outpatient clinics was experienced: *social environment, professional approach* and *value-adding measures.*

Social environment

A social environment including *a warm encounter, a familiar atmosphere* and *pleasant premises* was desired, and contributed to a positive experience of care. A warm and friendly encounter and atmosphere at nurse-led clinics, and a physical environment with pleasant premises designed to suit the patients' needs were described as important. In terms of contact with the clinic, the experience was affected by the way the person was received, how communication with them took place, what was shown and what was said. Behavior focused on the individual made the person feel acknowledged, and this formed the basis for a good relationship.

Professional approach

The nurses' professional approach was experienced in terms of *empathy, knowledge and skill,* as well as *support.* The nurses were described as sensitive, sympathetic and attentive in the sense that they took the patients' needs seriously, were well-informed about the patients' case history, were interested in their present situation, focused on conveying knowledge, support and trust, and made careful plans for further follow-ups. This contributed to competent and PCC based on the individual's unique experience of her/his disease and needs. The nurses' specialist rheumatology knowledge was also highly valued, as were their practical and teaching skills, which contributed to a positive experience of care. Practical and emotional support helped to ease the situation and take control of it.

Value-adding measures

The care was experienced to have added value as a result of measures which provided *security, accessibility* and *continuity.* A sense of security was perceived as facilitating daily life and promote positive emotions, trust, hope and confidence, which in turn encouraged contact and contributed to a good relationship between patient and nurse. The nurse-led clinics were accessible for visits and were easy to reach by telephone. The care was also accessed easily, in that patients were given help when they needed it and sufficient time was allocated for contact. Good continuity of care was experienced within the profession (among nurses) and between professions (nurses and other team members). Good continuity was valued highly at the nurse-led clinics, and meant that patients could see the same nurse, who also acted as a link with the physician and other team members involved in the care. These factors were presented as fundamental guarantees of safety in healthcare.

Living with persistent rheumatoid arthritis (Paper II)

The meaning of living with persistent RA appeared in four overall themes: *an existence dominated by painful symptoms and treatment, radical changes and limitations in one's life, a continual struggle to cope with life and to master the illness* and *a dependency on those who are close by and the world around.*

An existence dominated by painful symptoms and treatment

Living with persistent RA entailed an existence dominated by the constant presence of symptoms such as pain, fatigue and morning stiffness. *Pain* of varying degrees was experienced daily, either severe or dull, and often associated with swollen joints and reduced fine motor ability, strength, sensation or mobility. The pain was experienced as indescribably severe in periods of relapse, and sometimes during cold or hot seasons. Variations in pain presented a challenge in terms of planning daily activities. *Fatigue* was always present, making it increasingly difficult to do things and envisage solutions to everyday problems. *Morning stiffness* was painful and protracted. It took several hours to get the body going, which made it difficult to get up and follow morning routines. This appeared to progress as joints gradually became stiffer and lost their functions.

Pharmacological treatment dominated life, and the journey toward relief was long and painful. Side-effects could sometimes be worse than the illness itself. The addition of biological therapies could be helpful, though for some it was not; these treatments were experienced as anything from providing more freedom to being an encumbrance. Lack of positive effects from the medication, side-effects and frequent medication changes were experienced as frustrating and stressful.

Radical changes and limitations in one's life

Living with persistent RA entailed comprehensive changes and limitations to one's life situation. The illness started vigorously and was experienced as disabling from the beginning. It was difficult to accept that the body gradually weakened and felt tormented, tired and changed. It entailed negative consequences for everyday life in terms of ability to work, household chores, family relationships and personal finances. Loss of income and extra costs for medication, healthcare and home help meant their economic situation deteriorated. The illness and its treatment also affected teeth, sight and the skeleton, which was frustrating, made suffering worse and further exacerbated the life situation. Leisure time, travelling and social life were limited, leading to a sense of loss, loneliness and dejection. Obstacles to living as a couple included pain, lack of energy and feelings of insufficiency and worthlessness. The illness drained the energy considerably and reduced the ability to nurture the relationship. Thoughts about the future were characterized by uncertainty, worry and boredom.

The illness changed the perception of time, which was seen as both a constant lack of time and a painful waiting. Everything took longer, and time-saving routines were required. Appointments with the physician were not considered long enough. Adjusting and evaluating medical therapies was experienced as long and painful.

A continual struggle to cope with life and to master the illness

Persistent RA entailed a continual struggle to cope with life and to master the illness. It was a constant effort to mobilize the strength and resources to alleviate and normalize the situation. It was necessary to learn to live with the illness, to get to know one's body, its signals and limitations in order to be able to normalize everyday life.

Different solutions and strategies were used depending on the phase and severity of the illness. Good strategies were considered to include accepting the illness and trying to live as before. It was better to plan things and avoid stress. Remaining occupied was a diversion and a way of escaping the illness. Home adaptations and technical aids were seen as facilitating a transition from dependence to independence. Developing strategies and being inventive made things easier. A healthy diet and regular exercise were considered to promote wellbeing and were good for the joints. Social activities with others in the same situation boosted self-confidence and reduced the feeling of being alone with the illness. Thinking positively, retaining what gives pleasure, lowering one's level of ambition, and not being focused on results made things easier and provided hope for the future. Thinking that there were others who were worse off provided a sense of comfort and optimism.

A dependency on those who are close by and the world around

Living with persistent RA was experienced as increasing the dependency on those who are close by, on rheumatology care and on society.

The family's involvement was experienced as being very positive but it was difficult to be a burden for them. Support from, e.g., healthcare, home-help services, friends, and neighbors was needed.

Dependency on rheumatology care led to many contacts with the clinics, the experiences of which were ambivalent but important for everyday life in terms of diagnostics, treatment and care. Contact with healthcare services meant security. A positive approach had a calming effect, a sense of professionalism and of being taken seriously. Good coordination of services meant avoiding tiring waiting times. Support from, and accessibility of nurses provided a greater sense of wellbeing and security, as well as rapid solutions which saved time. Longer waiting times and lack of continuity in terms of physicians were felt to protract suffering and damage trust in the healthcare services. When the physicians' appointments were too short the possibility to provide understanding for one's own situation, feel confirmed as a person and influence one's care was limited. It was experienced that physicians' appointments had more focus on evaluating medications than on the person's life situation. The core of the conversation was considered stuck in the past, which was of limited interest to the person. There was a wish for HCPs to take more initiatives and to plan more for the future. It was experienced that access to and coordination of rehabilitation services, team care and patient education had been reduced, which led to delays in symptom management and recovery as well as compromised coping with everyday life.

A feeling of being opposed, disadvantaged and weakened occurred when the physician's decision was questioned by the social insurance agency. Feelings of being an encumbrance to society in terms of high treatment costs led to a sense of shame and powerlessness.

Towards measurement of person-centered care in nurse-led outpatient rheumatology clinics (Paper III)

Conceptual framework of PCC in outpatient rheumatology nurse-led clinics

Domain representation and theoretical underpinning

Considering empirical and theoretical data and taking a deductive logical reasoning approach, a preliminary PCC framework was formulated for nurse-led outpatient rheumatology clinics. The framework comprises five main aspects (domains): social environment, personalization, shared decision-making, empowerment and communication.

Social environment represents the way persons with RA are confirmed, received, approached and communicated with, as well as the conditions for good relationships and for establishing a warm, calm and friendly atmosphere. It also refers to the physical environment of the clinic in terms of ensuring integrity and pleasant premises.

Personalization represents the identification and recognition of the unique person's needs and concerns, preferences and values as well as abilities and capabilities. In this respect, the person is the most important source of information. Personalization is therefore dependent on communication between the person with RA and the nurse, i.e. the beginning of a partnership that creates conditions for planning person-tailored care. Personalization is facilitated when persons with RA feel confirmed, when they are given opportunities to tell their stories, when their problems are taken seriously, when their experiences are respected, when their self-knowledge is put to use and when their personal information is documented.

Shared decision-making represents a collaborative, interpersonal and interdependent process in which nurses communicate with patients in terms of potential care options and support them in their decision-making. This requires interaction and engagement, mutual respect and trust, as well as an effective exchange of knowledge and expertise. In the context of the meeting, shared decision-making involves strong collaboration between the nurse and the person with RA, understanding the person's situation, agreeing on care needs and planning, coordinating care and follow-up, sharing care information with other HCPs, family participation, and clarity over the person's responsibilities and opportunities in terms of influencing her/his care.

Empowerment represents the enabling of the person's resources and abilities, by actively engaging them to participate in their care and supporting them in taking action and taking control of their needs and life situation. Empowerment is an interactive process where nurses provide information, encouragement and support, and the person accepts shared or transferred power, autonomy and responsibility. In the context of the meeting, empowerment refers to involving the person with RA in taking an active role and influencing care planning and treatment, as well as supporting them in finding their own solutions. In addition, they need to be provided with opportunities to develop new knowledge and skills, and to acquire self-confidence and an ability to cope.

Communication represents the exchange of information, managing emotions and feelings, and creating a relationship between the person and the nurse. By listening, and by encouraging and involving the person with RA in dialogue, the person's narrative emerges and a common understanding is reached. Communication is considered a prerequisite for outpatient PCC, and is therefore embedded across all aspects of it.

In summary, the outpatient PCC framework focusing on the meeting can be conceptualized as holistic nursing in a partnership between the person with RA and the nurse. This comprises social environment, personalization, shared decision-making, empowerment, and communication.

Initial instrument development: item generation

The domains of the conceptual outpatient PCC framework were operationalized into a pool of 36 items. An individual review of the item pool by the expert group resulted in suggested revisions to simplify wording and ensure that it was consistent with the patients' perspective, and to emphasize that items related to outpatient nursing care. Conceptual mapping of items along the theoretical continuum from lower to higher levels of PCC revealed that items related to social environment and personalization represented a low-to-medium level of PCC, shared decision-making items represented a medium-to-high level, and items related to empowerment represented a high level of PCC. Communication was considered an integral aspect of most items and therefore cut across all levels. In this process, four items were discarded and the remaining 32 items were selected for further testing.

Evaluation of items and response categories

Participants completed the preliminary 32-item PCCoc/rheum with four-response categories in a mean of 5.3 minutes, and the two-category version in 4.3 minutes. Items were found to be easy to understand (77%) and relevant (93%), and the instructions were considered simple and clear (93%). Most participants (73%) preferred the four-category version.

A majority (77%) found that some items were redundant, and 20% of respondents considered that items were missing in terms of facilitating accessibility to care and care-related information and documentation. Following the addition of three items, no further suggestions were made. I-CVI values ranged from 0.87 to 1.00, and the S-CVI was 0.94.

Based on the results described above and on conceptual considerations, the preliminary PCCoc/rheum was revised into a 24-item version. This is presented in Table 4 together with its related domains.

Table 4.
Conceptual domain representation and associated PCCoc/rheum items

Domains		**PCCoc/rheum items (abridged)** [a]
Communication	*Social environment*	Welcoming care environment
		Undisturbed conversations
		Confirmed as a person
	Personalization	Understanding my situation
		Experiences are respected
		Problems are taken seriously
		Sufficient time allocated
		Equality in meeting
		Self-knowledge is considered
		Confident contacts with nurse
		Opportunity to tell my story
		Personal information documented
		Family participation
	Shared decision-making	Good nurse collaboration
		Care follow-up and documentation
		Needs determine care planning
		Care information shared as needed
		Coordinated care
		Agree with nurse on what to do
		Care responsibility is clear
		Information facilitating decisions
		Can influence care
	Empowerment	Gain new knowledge
		Strengthened ability to cope

[a] Items are conceptually but not individually ordered; gray areas represent items considered to overlap conceptually across adjacent domains. PCCoc/rheum, the Person-Centered Care instrument for outpatient care in rheumatology.

Measuring person-centered care in nurse-led outpatient rheumatology clinics (Paper IV)

Testing the measurement properties of the 24-item PCCoc/rheum

A total of 316 participants returned the initial questionnaire booklets (response rate, 92%), and 65% (n=207) consented to complete the PCCoc/rheum two weeks later.

The 24-item PCCoc/rheum displayed a relatively even distribution of item thresholds with no major gaps, spanning about eight logits. However, targeting was compromised at the lower end of the measurement range and it failed to represent higher levels of PCC (>4 logits), as illustrated by a mean (SD) person location of 3.2 (1.88) logits. Reliability was 0.88.

Twenty items exhibited fit residuals within the recommended range, and 22 items had non-significant chi-square values. Residual values and the associated ICC (Figure 2A) suggested that item 15 misfits, similar patterns were also seen for items 1 and 2, implying multidimensionality.

Items 5, 6 and 7 showed large negative residuals. However, these deviations were not statistically significant, and graphically the ICCs appeared acceptable (Figure 2B) and similar to items with good fit (Figure 2C). Furthermore, the impact of the observed dependency was negligible (see Paper IV for details).

There was no DIF by age, gender, disease duration, HAQ, DAS28, disease course (persistent vs. non-persistent disease) or time.

Response categories worked as intended with all items, except for item 15, where response category 1 was never the most likely outcome.

The empirical ordering of item locations from lower to higher levels of perceived PCC provided general empirical support for a priori expectations, except for items 1, 2 and 15 (Table 5).

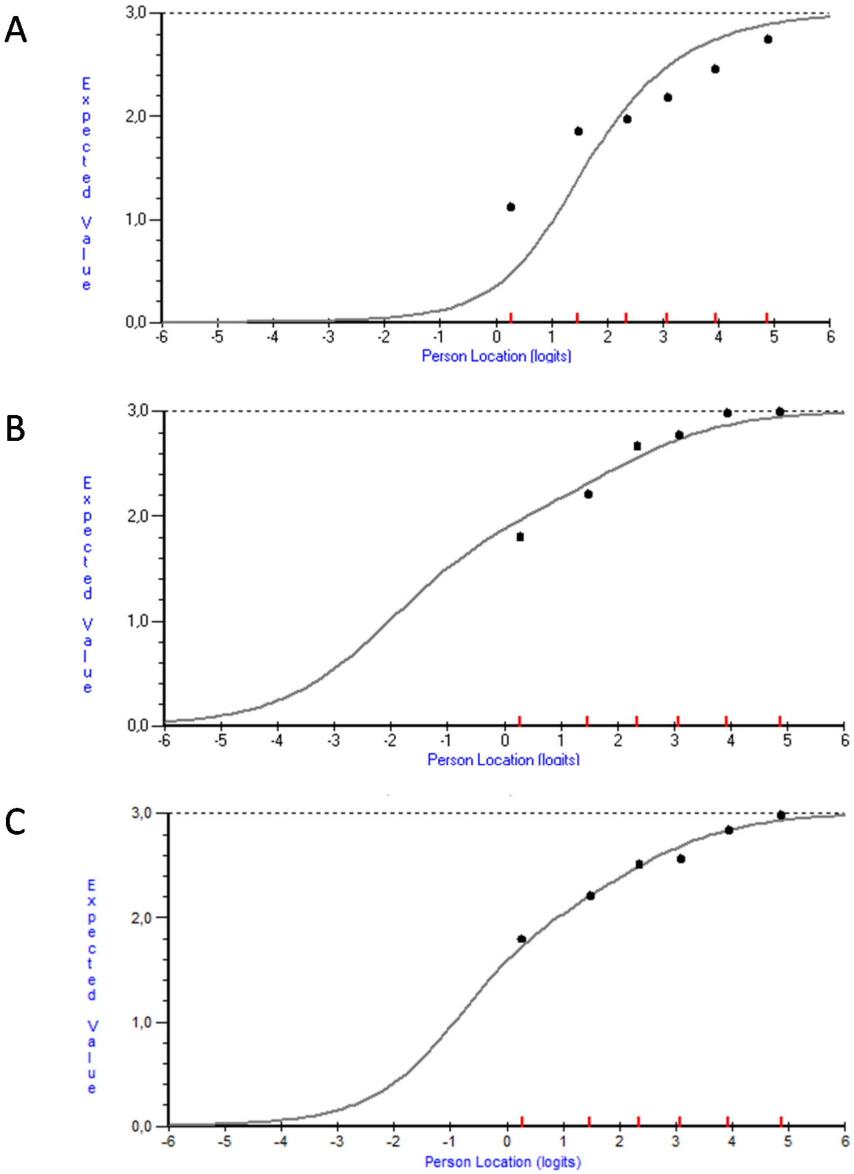

Figure 2.
ICCs representing PCCoc/rheum items 15 (panel A), 6 (panel B), and 17 (panel C). Gray curves (ICCs) represent expected item responses (y-axis) for each person location (x-axis) on the PCC continuum (positive values = higher levels of perceived PCC). Black dots represent the observed responses from groups of people at similar locations on the measured continuum (x-axis). Item 15 (panel A) displays a large positive residual and the graphical pattern suggests that this item does not represent the same construct as the PCCoc/rheum as a whole. Item 6 (panel B) has a large negative residual, although observed responses exhibit relatively minor deviations from the expected ICC. By comparison, item 17 (panel C) represents an item with good fit to the model.
ICC, Item Characteristic Curve; PCCoc/rheum, the Person-Centered Care instrument for outpatient care in rheumatology; PCC, Person-Centered Care

Table 5.
RMT item and fit statistics of the PCCoc/rheum

Items		24-item version			21-item version		
No.	Content (abridged)	Location	Fit residual	Chi-2 [a]	Location	Fit residual	Chi-2 [a]
4	Confirmed as a person	-1.43	-0.40	8.50	-1.35	0.40	12.79
9	Problems are taken seriously	-1.07	-1.17	2.43	-0.92	-0.82	2.16
7	Experiences are respected	-0.94	-2.60	9.46	-0.76	-2.27	5.18
6	Understanding my situation	-0.67	-3.39	17.73	-0.50	-3.15	8.44
3	Equality in meeting	-0.66	0.49	8.19	-0.49	1.90	13.32
20	Good nurse collaboration	-0.62	-2.15	14.76	-0.48	-1.15	10.64
16	Care follow-up and documentation	-0.46	-0.61	9.97	-0.28	0.06	4.73
11	Agree with nurse on what to do	-0.41	-2.08	8.51	-0.27	-1.13	4.86
18	Confident nurse contacts	-0.41	-0.96	8.81	-0.27	-0.62	4.17
8	Self-knowledge is considered	-0.34	-1.48	8.41	-0.14	-0.50	1.47
5	Opportunity to tell my story	-0.23	-2.83	17.85	-0.06	-1.37	7.63
19	Sufficient time allocated	-0.20	-0.92	15.14	-0.02	-0.20	2.61
10	Needs determine care planning	-0.05	-1.24	9.08	0.13	-0.23	7.02
24	Care information shared as needed	-0.03	-0.88	12.32	0.15	-0.05	4.66
14	Coordinated care	0.12	-1.53	14.45	0.33	-0.15	4.98
17	Care responsibility is clear	0.15	-0.13	6.22	0.34	1.28	9.76
22	Can influence care	0.34	-1.46	7.20	0.59	-0.50	6.34
23	Personal information documented	0.40	-1.51	9.42	0.62	-0.48	7.51
21	Information facilitating decisions	0.77	-1.83	17.09	1.01	-0.87	4.32
12	Gain new knowledge	0.87	0.17	10.39	1.15	1.98	8.58
13	Strengthened ability to cope	0.95	-2.10	7.33	1.22	-0.56	2.07
1	Welcoming care environment	1.04	3.45	19.10			
2	Undisturbed conversations	1.17	5.45	**104.09**			
15	Family participation	1.70	6.79	**81.01**			

[a] Values in bold indicate statistical significance at the 0.05 level following Bonferroni adjustment.

RMT, Rasch measurement theory; PCCoc/rheum, the Person-Centered Care instrument for outpatient care in rheumatology.

Revision of the 24-item PCCoc/rheum

Based on the analyses summarized above, items 1, 2 and 15 were omitted successively, and the PCCoc/rheum was assessed iteratively according to results from the quantitative analyses in interaction with conceptual considerations. This resulted in the omission of all three items and a 21-item PCCoc/rheum with a raw total score ranging from 0 to 63 (higher scores = greater degree of perceived PCC).

The person – item threshold distribution was similar to that of the 24-item version, with a mean (SD) person location of 3.59 (2.05) logits; reliability was 0.86. Model fit was generally good, with only one item (item 6) displaying an out-of-range residual value (Table 5). There was no DIF and all response categories worked as expected. Test-retest stability (intra-class correlation) of the raw total score was 0.82.

When item locations were ordered from lower to higher levels of perceived PCC (Table 5), a generally expected pattern emerged. Accordingly, the PCCoc/rheum continuum primarily represents aspects of personalization at the lower levels, then shared decision-making and finally empowerment at the higher PCC levels.

A lively discussion is usually helpful, because the hottest fire makes the hardest steel

Tom Clancy

Discussion

There is a need to measure person-centered outcomes in nurse-led outpatient rheumatology clinics from the patient perspective, and it is a priority in development and quality assurance of NLC.

The overall aim of this thesis was to describe and understand patients' experiences as a means to conceptualize and evaluate outpatient PCC in nurse-led clinics for patients with RA.

It assumes that developing a measurement instrument for this context involves identifying aspects of care which are essential for persons with RA and how PCC is conceptualized, and that the measurement properties of the new instrument should then be tested. It was therefore designed and conducted in two phases, one inductive and one deductive. The discussion of the findings follows the same structure.

Inductive phase

Using the patient perspective to conceptualize PCC and enable it to be measured

Increasing awareness of the value of PCC for persons with chronic conditions such as RA has the potential to drive important, long-term changes in clinical practice and delivery of rheumatology care. However, addressing needs and expectations in a humanistic way is dependent on understanding the patient's subjective experience of the illness and the clinical realities (Miles and Asbridge, 2016).

Qualitative research methods are recognized for improving how phenomena are understood, and for developing new knowledge from experiences by describing and interpreting multiple and diverse observations of phenomena (Malterud, 2001).

These types of insight were considered core elements in conceptualizing PCC and seeking descriptors of the latent PCC variable. To enable this, two phenomena were studied from the patient perspective. The first involved the experience of care offered by nurse-led rheumatology outpatient clinics (Paper I). At the time of planning this research, studies were only available from a few countries and little was known about nurse-led rheumatology clinics in a Swedish context. The second involved the meaning of living with severe, persistent RA (Paper II). In this case, there was a lack of studies about the meaning of living with active disease course. It was therefore considered a priority to take into account the perspective of patients with the most obvious healthcare needs (i.e. those with persistent RA).

Using appropriate qualitative research methods according to the aims (Fridlund and Hildingh, 2000), empirical qualitative data were collected, processed, summarized and organized to help understand the aspects of care which persons with RA consider essential. Using qualitative content analysis according to Burnard (1991), the experience of care in nurse-led clinics (Paper I) was described in terms of what was experienced as positive and as less positive, what happened in these situations and the feelings it created. The meaning of living with persistent RA (Paper II) was analyzed using the hermeneutical phenomenological method, which combines descriptive and interpretive elements to transform personal meanings and experiences from interview texts into understanding (van Manen, 1997).

Understanding the aspects of care that persons with RA experience as essential

Understanding what PCC means for the persons with RA is a prerequisite for knowing what they expect from it, and for finding the most appropriate way of measuring it (de Silva, 2014).

NLC was found to be a highly valued part of the *care continuum* and of everyday life (Papers I-II). A warm and confirming encounter, familiar atmosphere and pleasant premises were desired, and empathy, knowledge and skill were highly valued in nurses, as well as their willingness to support. These factors contributed to a professional and person-centered NLC. Accessibility to and good continuity at nurse-led clinics were found to add value and to provide a sense of wellbeing and security.

Persons living with persistent RA did not consider that current rheumatology care met their needs sufficiently (Paper II). Life is a constant struggle. They have to tolerate a painful *disease continuum* and mobilize strength and resources they did not know they had. They are constantly busy looking for solutions and strategies to alleviate their condition, master their illness and normalize their situation. According to Frankl (2006), there is a struggle when there is something to fight for, to achieve or to prevent. This is part of life, and the ability to struggle is a principal condition for survival and for finding a way back to meaning in life. An important task for nurses is to listen to the person's narratives and experiences in order to identify strengths and help them facilitate available resources to achieve a more comfortable existence.

From the perspective of the lifeworld and the four fundamental existentials described by van Manen (1997), the impact of persistent RA affects sufferers' bodies, their relationships, and the space and time in which they live (Paper II).

The lived body is experienced as tormented, tired, weakened and changed by living with constant symptoms such as pain, fatigue and stiffness. The disturbed relationship between the lived body and the lifeworld diminishes the person's control over life situations. This points to the importance of involving the persons with persistent RA in their care, and supporting them to cooperate with their bodies in order to cope with daily life. Similarly, depending on the person's experience, clear information about the possibilities and limitations of therapy appears to facilitate coping and decision-making in terms of treatment and care.

Lived human relationships are affected by persistent RA in the sense that it leads to increasing dependence on family, care and society. The person often feels they are draining the resources of others rather than replenishing them, and additional healthcare support is needed, but it is not always forthcoming in the way they expect. This highlights the importance of a person-centered care approach, including partnership based on mutual respect, trust and reliance (Ekman et al., 2011; McCormack et al., 2006).

The lived space is affected by illness-related needs and limitations, and accommodation and technical aids may be required to make the patient more independent. Van Manen (1997) points out that there is a difference between the real and the subjectively experienced world. Supporting person with persistent RA in recognizing the possibilities rather than dwelling on the obstacles can help make them less resistant to using technical aids or home adjustments.

Lived time reflects a subjective perception of the past, the present and the future. For persons with persistent RA it is important to move forward, yet HCPs are often seen to be emphasizing the past. Waiting times are considered too long that they feel they have not time to wait. Sufficient time should therefore be allocated for contact in order to capture patients' life histories and develop a beneficial, respectful meeting focusing on the present and future rather than the past.

Taken together, the understanding which emerges from empirical qualitative data about essential aspects of care for persons with RA illustrates the importance of more PCC-oriented care for patients with RA. Furthermore, the narratives and findings from these studies provide rich source material for moving towards a conceptualization of outpatient rheumatology PCC from the patient's perspective.

The person-centered meeting in outpatient NLC

Papers I and II illustrate that persons with RA attach major importance to meetings with the nurse. These meetings are also a natural part of the necessary care environment for initiating, planning, delivering and following up on PCC. According to McCormack (2004), the care environment has a major impact on the operationalization of person-centered nursing, and has the greatest potential to limit or facilitate person-centered activities or processes. The care meeting between the patient and the nurse was therefore the specific context chosen for conceptualizing outpatient PCC in nurse-led rheumatology clinics.

Persons with RA need repeated contact with nurse-led clinics, and well-functioning services are therefore very important (Papers I-II). The experiences they accumulate over the course of living with the disease make them more unique during the journey, and the importance of personalization and adaptation of care to their individual needs becomes clear.

Person-centered meetings are desirable in terms of focusing on the person and her/his life situation as a whole (Papers I-II). The meeting should be planned and structured in accordance with the needs of the persons, in mutual agreement and with respect for the past, the present and the future. Time is considered of major importance for person-centered meetings. Sufficient time must be allocated for the meeting to establish a good partnership, capturing the persons' life histories, involving them in their own care, sharing decision-making in terms of planning care, and at the same time supporting and strengthening the person. In outpatient care for people with chronic diseases, each appointment usually builds on the previous one, which implies a long-term rather than an appointment focus, as the accumulated knowledge and experiences are central to personalization from the perspectives of both the person and the HCP (Starfield, 2011). At the same time, due to the consequences of RA and the complexity of needs, the rheumatology care takes gradually a larger space in the daily life, and patients need more clinic appointments in order to cope, which illustrates the important role of nurse-led clinics (Arvidsson et al., 2006).

Care meetings are associated with great expectations of positive outcomes (Papers I-II). A person-centered meeting facilitates this by shifting from "medical decisions" to "person-centered decisions", with the potential to transform patients' experience of care and illness. It also contributes to HCPs experiencing an increased sense of meaning (Clayman et al., 2017).

Deductive phase

The conceptual framework for PCC in outpatient rheumatology nurse-led clinics

The proposed conceptual PCC framework for outpatient care focuses on the care meeting between the patient with RA and the nurse, and on the patient as an active part of a holistic nursing in partnership. Therefore, the PCC framework does not aspire to covering the full PCC spectrum, but focuses on the meeting, taking into account a person's life situation as a whole. This is in line with the collaborative nature of PCC and with the view of the person as the most important source of information in the care process (Coulter et al., 2015).

The framework was conducted through a process of deductive theoretical reasoning which aimed to identify aspects (domains) of PCC. Using the perspective of patients with different levels of disease burden (from patients in remission to patients with severe, persistent RA), and taking into account their experiences of care and living with the disease (Papers I and II), as well as experiences described in other rheumatology nursing research (Larsson et al., 2014; Larsson et al., 2012; van Eijk-Hustings et al., 2013; van Eijk-Hustings et al., 2012; Ryan et al., 2013; Ryan et al., 2006a ; Primdahl et al., 2011; Arvidsson et al., 2006; Arthur and Clifford, 2004; Hill, 1986), the aspects of care most crucial from a person-centered perspective were identified and conceptualized as five interrelated domains: social environment, personalization, shared decision-making, empowerment and communication.

The domains are aligned with holistic nursing by considering all four constructs of the person-centered nursing framework (McCormack and McCance, 2006), and with a holistic partnership and co-creation of care by considering the Gothenburg PCC model (Ekman et al., 2011). These conceptual linkages add perspective to the framework and make it useful in facilitating a person-centered perspective in clinical practice, as well as in more consistent and systematic implementation of PCC.

Although the framework is likely to be challenged and subject to further development, it appears to be the first of its kind. As such, the resulting clarity over the concept of outpatient PCC is likely to contribute to progress in PCC practice, evaluation and measurement.

Developing an instrument to measure outpatient PCC from a patient perspective

The domains of the framework were further operationalized by developing items into an instrument intended to represent the framework. Conceptual mapping of items from lower to higher levels of PCC revealed a structure among the domains of the outpatient PCC framework; they are interrelated, and the way they are ordered is hypothesized to represent a clinically relevant and logical continuum of outpatient PCC. In the process of item generation, four of the five domains were seen as hierarchically interrelated but distinct (social environment – personalization – shared decision-making – empowerment) while the fifth domain (communication) was seen as embedded across all aspects of outpatient PCC. The suggested order was considered to represent a theoretical and clinical development from lower to higher degrees of perceived PCC. This can be considered a prerequisite for defining a valid quantitative construct, which is a fundamental building block towards measurement (Wolfe and Smith, 2007; Wilson, 2005). Furthermore, the generated items were found to have good content validity and were perceived as relevant and easy to use by persons with RA (Paper III). Moving beyond the suggested outpatient PCC framework, the items are substantiated by the principles of PCC (WHO, 2015) and person-centeredness (McCormack et al., 2015). This means that they are thought to have the potential to be person-centered as they are formulated from the perspective of the person and in the light of the principles and values of PCC and person-centeredness (i.e. respectful, tailored, holistic, collaborative, ethical, empowering and co-produced). Taken together, this suggests that the items align with the intentions of the underpinning conceptual framework.

PCCoc/rheum: a new measurement instrument

The conceptual PCC framework for outpatient care in rheumatology was operationalized into a set of items called the PCC instrument for outpatient care in rheumatology (PCCoc/rheum), and the hypothesis was that it would be useful as a new person-centered outcome measure of patient-perceived PCC in nurse-led outpatient rheumatology clinics.

Empirical testing of the extent to which the PCCoc/rheum items worked together as expected, as a measurement instrument, and in terms of representing a *quantitative continuum*, provided general support for its appropriateness. However, the analyses also identified areas for revision, which resulted in a 21-item PCCoc/rheum that maps out the underpinning conceptual PCC construct as expected, and exhibits promising measurement properties.

Three items exhibited signs of multidimensionality. Two of these (items 1 and 2) were the sole specific representatives of the social environment domain, primarily representing physical environment. A review of these items revealed that the aspect they represented could be argued to go beyond the patient/nurse meeting which is a core target of the PCCoc/rheum.

Moreover, a further review of the full item set suggested that other aspects of the social environment domain were embedded across other PCCoc/rheum items, e.g. respect, empathy, sensitivity, kindness. It therefore made not only quantitative but also qualitative and theoretical sense to omit these items.

Similarly, item 15 also represents something external to the patient/nurse meeting. While the involvement of family members in inpatient care is considered an important aspect of PCC (Ekman et al., 2011), it is dependent on whether the patient has a relevant family member and if so, whether s/he wants that person to participate. While family involvement is experienced as positive, persons with RA also value the support from healthcare services in that it can alleviate the burden on relatives and friends (Paper II; van Eijk-Hustings et al., 2013). Outpatient visits are usually planned on a continuous basis, and family members may not always be considered a priority, or they may be considered more important at home. Therefore, while this item is still part of the underpinning general conceptual outpatient PCC framework, it appears reasonable to delete it. This does not mean that nurses should disregard whether patients want to involve family member(s), as this may be of great importance to the individual patient. However, the item is not productive in the process of measuring PCC as represented by the PCCoc/rheum.

As a consequence of the deleted items and associate conceptual considerations, the PCCoc/rheum framework was also slightly revised in terms of social environment, which was reconsidered in a way similar to the communication domain. Figure 3 represents the revised version of the conceptual framework underpinning the PCCoc/rheum. Importantly, the deletion of items 1, 2 and 15 did not affect the measurement properties of the PCCoc/rheum notably. In fact, the conceptual clarity of the revised measure could actually be said to have been enhanced by item deletion, as the revised instrument is in better accordance with the underpinning outpatient PCC framework and focuses more clearly on the patient/nurse meeting.

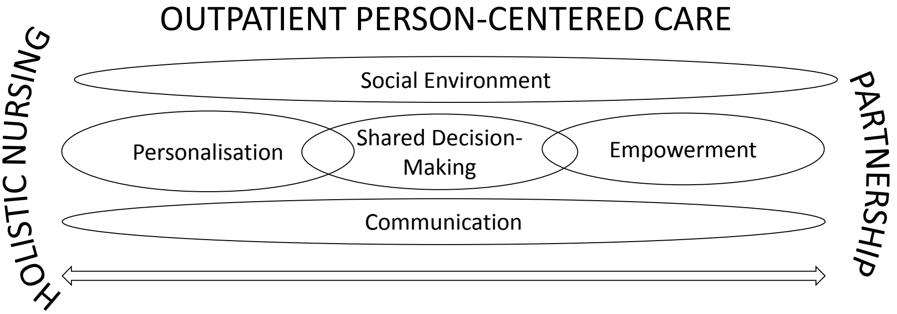

Figure 3.
Graphical illustration of the conceptual framework of outpatient person-centered care in nurse-led rheumatology clinics, focusing on the person/nurse meeting that underpins the Person-Centered Care instrument for outpatient care in rheumatology (PCCoc/rheum).

Although the analyses provided support for the PCCoc/rheum as a measurement instrument, areas in need of further attention were identified. In particular, there was a targeting problem in that the levels of PCC were perceived as higher than those operationalized by the PCCoc/rheum. This means that persons located at the upper end of the PCC continuum are measured with relatively low precision (Hobart and Cano, 2009). However, this is considered to be a relatively minor concern given the primary purpose of the PCCoc/rheuma, i.e. to measure patient-perceived levels of PCC as a means of quality assurance and to identify areas for improvement. However, the fact that there were very few people located at the lower end of its measurement range means that the evaluation of items at this end of the continuum is compromised (Hobart and Cano, 2009). Additional data collections will therefore be needed, including a wider range of clinics which also represent lower levels of PCC.

However, and importantly, our observations suggest that the PCCoc/rheuma successfully represents the underpinning conceptual outpatient PCC framework. This conclusion is based on the generally good correspondence between theoretical expectations and empirical item locations. Empirical item ordering provides a description of what happens when patient-perceived PCC goes from lower to higher levels. By analogy, the item hierarchy may thus be viewed in terms of a theoretically corroborated PCC road map. That is, the outpatient PCC journey begins with the meeting between the person with RA and the nurse, where the unique person is confirmed in terms of her/his experiences, preferences, values and problems (e.g. item 4: "affirmed as a person"). This then develops into a partnership aimed at collaboration in identifying and managing the person’s individual needs. Finally, higher levels of PCC strengthen the person and her/his capacity and preparedness (e.g. item 13: “strengthened ability to cope”).

Taken together, the findings discussed above provide support for the two hypotheses that emerged during the process of this thesis. These are: (i) the conceptual outpatient PCC framework could be operationalized into a measurement instrument through descriptors (items) of aspects of care that can be related to the unique person with RA and (ii) the measurement instrument represents the hypothesized PCC framework and can be used as an instrument for measuring PCC at nurse-led rheumatology clinics.

Several aspects of the PCCoc/rheum appear to make it a novel type of PCC outcome measure. First, it is based on a specific outpatient PCC framework developed through theoretical reasoning, combining available theoretical standpoints with direct patient narratives. Second, patient participation was central to the conceptualization, development and evaluation of the PCCoc/rheum, as it was developed in collaboration with patients with different levels of RA burden by taking into account the aspects of care they themselves identified as essential from a person-centered perspective. Third, operationalization of the measure was guided by fundamental measurement principles, as articulated through RMT. Finally, empirical iterative RMT-based testing of the measurement properties of the PCCoc/rheum, in interaction with conceptual considerations, yielded results in support of its conceptual and metric integrity. Taken together, these features appear to set the PCCoc/rheum apart from available instruments which aim to target PCC from a patient perspective (Edvardsson et al., 2009; Suhonen et al., 2005; Coyle and Williams, 2001). The developmental process of the PCCoc/rheum is illustrated in Figure 4. This process conforms to the one prescribed by the US Food and Drug Administration (FDA, 2009) in order to support claims based on patient-reported outcome measures. It therefore seems reasonable to argue that the developmental process has contributed to ensuring that the resulting measure will be relevant to persons with RA who use nurse-led outpatient services, and that it will be useful in setting goals, monitoring quality of care and identifying areas for improvement.

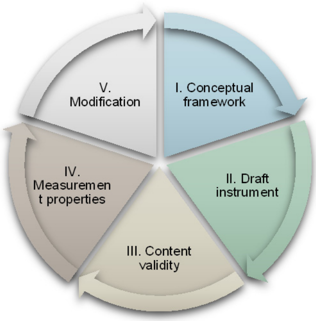

Figure 4.
Development process of the Person-Centered Care instrument for outpatient care in rheumatology (PCCoc/rheum)

Tomorrow is the most important thing in life. Comes into us at midnight very clean. It's perfect when it arrives and it puts itself in our hands. It hopes we've learned something from yesterday.

John Wayne

Clinical and research implication perspectives

Identifying person-centered outcomes that are relevant and measurable has been in focus in this thesis in order to address existing gaps in outcome measurement from a person-centered perspective in outpatient rheumatology nurse-led clinics.

A conceptual framework for outpatient PCC, and a new measurement instrument for perceived degree of PCC in outpatient care in rheumatology (the PCCoc/rheum) have been developed. This progress should be seen as a beginning in this specific area of outpatient rheumatology care and as in need of further development. However, the longer term importance of this progress has to be considered from several perspectives.

Patient perspective

Patients with chronic diseases need care that meets their needs and expectations throughout their life with the disease. The conceptual outpatient PCC framework contributes to clarifying and explaining what outpatient PCC means. This has great value for forming and rethinking the patients' role in nurse-led clinics and adapting the services accordingly.

Patient-reported experience measures (PREMs) provide insights into the patients' experience of their care, and capture patients' evaluation of care. (Nilsson et al., 2016). PREMs are increasingly regarded as indicators of the quality and safety of care (Weldring and Smith, 2013). For example, most national quality registers in Sweden plan to extend their array of PREMs and to increase the use of patient-reported data as a basis for quality assurance (Nilsson et al., 2016). The PCCoc/rheum is a new PREM with potential to provide the person-centered perspective by offering the opportunity to systematically involve patients in the evaluation of care in nurse-led rheumatology clinics. Many patients want to play a more active role in their care and influence its quality by expressing their own perspective, which is crucial in order to appreciate the whole and understand what is best for them. The PCCoc/rheum promotes a more collaborative approach and better partnership, and may serve as a person-centered complement to clinical and biomedical outcome measures in the care of patients with RA.

Implementation perspective

In Sweden, there are national quality registers for a number of diagnoses, including RA, and the country exemplifies in many ways the usefulness of register data in national healthcare quality comparisons (Nilsson et al., 2016). However, currently, collected data mainly concern medical-, disease- and treatment-related information, while nursing-related activities are underrepresented (Swedish Society of Nursing, 2007). The PCCoc/rheum has the potential to fill this gap in rheumatology as it is suitable for monitoring PCC in the Swedish RA national quality register. Incorporating the PCCoc/rheum in the registry would enable evaluations and comparisons of rheumatology nursing outcomes both at the individual and group levels, as well as serving as a source for further research.

The PCCoc/rheum might also be tested in patients with other rheumatic diseases. While such disorders differ substantially, their management is similar from a nursing and person-centered perspective. Furthermore, while the PCCoc/rheum was developed for and tested within the context of nurse-led outpatient rheumatology clinics, it is appropriate to consider the generalizability of the underpinning conceptual framework to outpatient care of persons with other long-term disorders. That is, the suggested conceptual framework for outpatient PCC may also be applicable beyond rheumatology care, as well as beyond nurse-led clinics. However, at this point the usefulness of the PCCoc/rheum in other contexts is to be considered hypothetical and in need of empirical testing.

Healthcare organization perspective

The conceptual framework of outpatient PCC argues for and supports a more active involvement of patients with RA in clinical practice, as well as in the design, planning, implementation and evaluation of healthcare services. It also highlights an empowering, shared-decision making and integrating care climate based on healthful relationships between patients, nurses and other HCPs, as well as between different healthcare providers. Such integrated collaborations have been challenging so far in outpatient care due to an increased fragmentation of care delivery that is often based on organizational divisions instead of the patient's needs, without the possibility of assuming overall responsibility. This makes it difficult to overlook, manage and coordinated different specialist areas around the needs of patients with chronic disorders, who therefore consider themselves less involved in their own care (Docteur and Coulter, 2012). Reorientation of care towards more outpatient care during the last few decades necessitates a more holistic management approach to overcome the fragmentation. The outpatient PCC framework promotes a holistic approach to care, and the PCCoc/rheum may contribute to identifying and monitoring existing critical integration and coordination issues. However, significant attention must be focused on adopting and enabling a person-centered culture which is a key prerequisite for organizations to promote person-centeredness. Therefore, both frameworks (e.g., the outpatient PCC framework) and outcome measures (e.g., the PCCoc/rheum) are useful in implementing PCC as well as in reconfiguring the organization of care to achieve this goal.

Societal perspective

To better serve the population, new person-centered approaches to care have been required to ensure that care is delivered within a humanistic framework of clinical practice that recognizes the importance of evidence-based care in a manner that respects the patient as a person (Miles and Asbridge, 2016). In other words, healthcare services should take full account of patients' values, preferences and goals, and should also respond to emotional, psychological, spiritual and social necessities in addition to physical needs. In this context, monitoring the performance and quality of care is central. The PCCoc/rheum may be useful for this purpose in outpatient care. It may thus contribute to creating more equitable and accessible outpatient health services that better coordinate care around people's needs and lead to improved health outcomes and experiences for people with chronic conditions such as RA. The conceptual outpatient PCC framework may also influence education and policy development by conveying a more engaging, humanistic and ethical view that promotes more active and healthy living, with reduced dependency on specialist care.

Measurement perspective

Patient experience is associated with health outcomes, and information about patient outcomes is increasingly needed for improving care policy and practice (Cano et al., 2017). For example, the Organisation for Economic Cooperation and Development (OECD) states that patient-centered outcome measurement has an important role in the benchmarking of healthcare systems (OECD, 2017).

The PCCoc/rheum is such a measurement instrument, developed within a relevant partnership, for measuring the patients' experience of received PCC. However, it is also in need of further evaluation and possibly development in order to make it more robust. Further studies are needed and should include a wider range of clinics that also represent lower levels of PCC. Such work may be facilitated by incorporating the PCCoc/rheum in the Swedish national RA register. Furthermore, the PCCoc/rheum needs to be calibrated in order to achieve stable conversion of raw scores to linear measures. Further research is also needed to better understand how the perceived degree of outpatient PCC relates to other outcomes, such as quality of life and limitations in daily life activities.

Conclusions

The experiences of the persons with rheumatoid arthritis (RA) highlight the need for a holistic and person-centered approach to care which emphasizes the unique person's needs and preferences, and which improves individual outcomes, as well as the management and quality of arthritis care. The social environment, professional approach and value-adding measures are experienced as particularly relevant for optimal nurse-led rheumatology outpatient care. Person-centered care (PCC) is seen as a holistic complement to conventional clinical practice, and its use and evaluation in the care of patients with RA is desirable. In this process, the organization of care and the role and skills of the nurse should focus on the individual's needs and perspectives, rather than on the disease.

Living with persistent RA constitutes a radically changed and limited existence dominated by the constant presence of symptoms and a long and painful journey toward alleviation. Life is a constant struggle to normalize the life situation, master the illness and cope with being dependent on relatives, healthcare services and society. Persons with persistent RA find current rheumatology care insufficient in meeting their needs. This implies that persons with persistent RA have particular needs which require personalized care. The experience of persons with RA and their lifeworld are important sources of knowledge in generating understanding and action based on insights about the person's reality. The outpatient care meeting should thus be person-centered with a holistic focus, making use of the person's narrative about her/his life, establishing a good partnership that promotes security and participation, and planning care and treatment together with the person.

A conceptual PCC framework was proposed which focused on the care meeting in the context of the outpatient setting and rheumatology nurse-led clinics. It comprised five interrelated domains: social environment, personalization, shared decision-making, empowerment and communication. These were further operationalized into a proposed instrument for measuring outpatient PCC, called the PCC instrument for outpatient care in rheumatology (PCCoc/rheum). The proposed PCCoc/rheum was found to have good content validity and was perceived as relevant and easy to use by persons with RA.

The PCCoc/rheum exhibits good measurement properties and its items correspond to the underpinning conceptual outpatient PCC framework. As such, it provides an opportunity for combining disease-related and other traditional outcomes with more personalized care-related outcomes. In particular, the PCCoc/rheum enables measurement of aspects of nursing care which are traditionally difficult to measure. The PCCoc/rheum is expected to be useful for clinical as well as research purposes in terms of monitoring person-centered outcomes as an indicator of the quality of care. As such, it represents a patient-reported instrument developed to contribute to the evaluation of nurse-led clinics from a new person-centered perspective, and has the potential to contribute to facilitating and developing PCC.

Taken as a whole, the work presented in this thesis shows that persons with RA have to cope with an existence characterized by a *disease continuum* and a *care continuum,* and that their experience can be taken into account to map out a *continuum of person-centered care* that represents a path from experience to measurement.

Populärvetenskaplig sammanfattning

Personcentrerad vård anses vara en nyckelkomponent inom hälso-och sjukvården som kan bidra till förbättrade utfall för patienterna, bättre vårdkvalitet och kostnadseffektivitet. Konceptet innebär ett skifte i vårdperspektiv genom att ha sin utgångspunkt i ett humanistiskt och etiskt präglat förhållningssätt, vilket förenklat har uttryckts som att utgå från personen med sjukdomen i stället för sjukdomen som personen har. Vården skräddarsys således kring personens behov och förväntningar och bedrivs tillsammans med personen som är aktivt involverad i all planering och genomförande. Som vårdkoncept är personcentrerad vård komplext och det saknas consensus kring vad konceptet innebär inom olika vårdområden. Detta har försvårat såväl systematisk implementering inom klinisk praxis som utvärdering av resultat och personcentrerad vård anses underutvecklad ur dessa avseenden.

Inom reumatologisk vård har det under de senaste två årtiondena skett positiva förändringar med betydande läkemedelsutveckling och nya behandlingsstrategier. Det finns emellertid även utmaningar relaterade till ökade tillgänglighetskrav, brist på reumatologer och ett skifte från inneliggande vård till öppenvård med ökad arbetsbelastning inom öppenvården. Förändring och anpassning av öppenvårdsorganisationen har därför varit nödvändig och nya vårdmodeller har behövts för att möta kvalitetskraven. Sjuksköterskeledd vård är en sådan modell som anses effektiv, acceptabel och säker och har därför fått allt större plats i vården av patienter med reumatiska sjukdomar, såsom reumatoid artrit eller ledgångsreumatism. Sjuksköterskeledd vård är samtidigt i behov av utveckling och kvalitetssäkring för att säkerställa hög kvalitet på omvårdnaden inte minst för att personcentrerad vård inom reumatologi fortfarande anses vara ett otillfredsställt behov. Ett mätinstrument som erbjuder möjlighet att följa upp vården från patientens perspektiv är därför en hög prioritet för att bättre förstå fördelarna med och vidareutveckla sjuksköterskeledd reumatologisk öppenvård.

Det övergripande syftet med denna avhandling var att beskriva och förstå patienternas upplevelser för att begreppsliggöra och utvärdera personcentrerad vård på sjuksköterskemottagningar för patienter med reumatoid artrit i öppenvård.

Avhandlingen omfattar fyra delarbeten som bygger på varandra med en tydlig inbördes logik.

I delarbete I intervjuades 18 personer med RA avseende hur de upplevde vården i sjuksköterskeledd reumatologisk öppenvård. Resultatet visade att human miljö, professionellt förhållningssätt och värdeskapande åtgärder har speciellt stor betydelse för en optimal vård och att detta relaterar till graden av personcentrering i omhändertagandet. Den humana miljön upplevdes som positiv och omfattade varmt bemötande, familjär stämning och trivsamma lokaler. Sjuksköterskornas professionella förhållningssätt bidrog till att patienterna upplevde empati, kunskap och skicklighet samt stöd. Vården beskrevs som personcentrerad och kompetent genom att den utgick från personernas unika sjukdomsupplevelse och behov. Sjuksköterskornas specifika kunskaper inom reumatologi och specifik reumatologisk omvårdnad värdesattes högt. Vården var värdeskapande för patienterna. Den ingav trygghet, förtroende, hopp och tillit. Den förenklade patienternas vardag och skapade positiva känslor. Sjuksköterskemottagningarna upplevdes ha god tillgänglighet och kontinuitet.

I delarbete II intervjuades 10 personer med svår, ständigt symtomgivande reumatoid artrit (så kallad persisterande) avseende innebörden av att leva med sjukdomen. Resultatet visade på en tillvaro dominerad av plågsamma symtom och behandling, genomgripande förändringar och begränsningar av livssituationen, en ständig kamp att hantera livet och bemästra sjukdomen, samt ett beroende av omgivning och omvärld. Resultaten visade även att befintlig vård har svårt att möta behoven hos personer med persisterande reumatoid artrit och pekade mot behovet av en mer personcentrerad vård. Bristande kontinuitet och ökade väntetider upplevdes förlänga lidandet och skadade förtroendet för vården. Det avsattes inte heller alltid tillräckligt med tid för besöken, vilket begränsade möjligheten att kunna skapa förståelse för den egna situationen, bli bekräftat som person eller kunna påverka sin vård. Återbesöken upplevdes ha fokus på tidigare händelser, medan det fanns en önskan att vårdpersonalen hade mer fokus på nutid, tog fler initiativ, erbjöd lösningar och planerade för framtiden.

Baserat på de första två delarbetena och på befintliga teorier avseende personcentrerad vård och personcentrering utvecklades i delarbete III ett ramverk för personcentrerad vård i sjuksköterskeledd reumatologisk öppenvård. Ramverket har utgångspunkt i vårdmötet och ser patienten som en aktiv partner i vårdprocessen. I denna kontext begreppsliggörs personcentrerad vård som holistisk omvårdnad i ett partnerskap mellan personen med RA och sjuksköterskan. Ramverket innefattar fem relaterade och överlappande områden: human miljö, personalisering, delat beslutsfattande (så kallad shared decision-making), bemyndigande genom patientmedverkan (så kallad empowerment) och kommunikation. Utifrån detta ramverk utvecklades ett instrument för att mäta graden av patientupplevd personcentrerad vård i sjuksköterskeledd reumatologisk öppenvård. I instrumentutvecklingen deltog såväl patienter som vårdpersonal. Det nyutvecklade instrumentet som benämns PCCoc/rheum (efter sitt engelska namn Person-Centered Care for outpatient care in rheumatology) utvärderades först bland 50 personer med reumatoid artrit och resultaten visade på god användarvänlighet och innehållsvaliditet.

I delarbete IV testades mätegenskaperna för det nyutvecklade instrumentet i ett urval av 316 personer med reumatoid artrit från sex olika sjuksköterskeledda öppenvårdsmottagningar. Resultaten visade att PCCoc/rheum tycks motsvara det grundläggande ramverket med avseende på patient-/sjuksköterskemötet. Mätegenskaperna var generellt goda och PCCoc/rheum kan generera linjära mått som fungerar på samma sätt och har samma innebörd i olika kliniskt relevanta subgrupper. PCCoc/rheum har således potential att fungera som ett mätinstrument för utvärdering av patientupplevd personcentrerad vård på sjuksköterskemottagningar i öppenvård.

Patienters upplevelser och livsvärld är viktiga kunskapskällor som genererar förståelse och handling baserat på insikter om personens verklighet. Upplevelsen av vård och sjukdom hos personer med RA stödjer att personcentrering har en central roll i deras vård och understryker behovet av ett holistiskt och personcentrerat förhållningssätt. PCCoc/rheum är ett nytt mätinstrument som har utvecklats för att bidra till utvärdering av vården på sjuksköterskemottagningar i öppenvård från ett personcentrerat perspektiv. Instrumentet möjliggör mätning av aspekter av omvårdnad som traditionellt är svåra att mäta och kan ses som komplement till andra kliniska, patientrelaterade och biomedicinska utfallsmått. Avsikten är att PCCoc/rheum ska användas i såväl klinisk praxis som forskning som en indikator för vårdens kvalitet, med huvudsaklig tillämpning på klinik-, sjukhus- eller organisationsnivå, t ex genom implementering i nationella kvalitetsregister.

Ad infinitum

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When you want something, all the universe conspires in helping you to achieve it.
Paulo Coelho

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>
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DESSA PÅSTÅENDEN HANDLAR OM VÅRDEN HOS SJUKSKÖTERSKOR PÅ DIN REUMATOLOGIMOTTAGNING

TÄNK PÅ ATT ENDAST KRYSSA FÖR ETT ALTERNATIV FÖR VARJE PÅSTÅENDE!

1. Vårdmiljön är inbjudande för mig
2. Samtalen med mig sker i ostörd miljö
3. Jag är en jämbördig part i mötet med sjuksköterskan
4. Jag bekräftas som person
5. Jag får utrymme att berätta hur jag har det
6. Min berättelse skapar förståelse för min situation
7. Min erfarenhet respekteras
8. Min kunskap om mig själv tas tillvara
9. Mina problem tas på allvar
10. Mina behov styr planeringen av min vård
11. Jag och sjuksköterskan är överens om vad som ska göras
12. Jag lär mig nytt i mötet med sjuksköterskan
13. Min förmåga att hantera min situation stärks
14. Min vård samordnas på bästa sätt
15. Mina närstående ges möjlighet att medverka i min vård om jag så önskar
16. Min vård följs upp och dokumenteras
17. Min del av ansvaret för min vård är tydlig
18. Jag har trygga kontakter med sjuksköterskan
19. Jag får tillräckligt med tid i mötet med sjuksköterskan
20. Jag och sjuksköterskan har ett gott samarbete
21. Jag får information som underlättar för mig att ta beslut om min hälsa
22. Jag kan påverka min vård
23. Information om sådant som är viktigt för mig dokumenteras
24. Information om min vård är tillgänglig för den personal som berörs

Svarsalternativ

Stämmer inte alls = 0
Stämmer inte särskilt bra = 1
Stämmer ganska bra = 2
Stämmer helt och hållet = 3

Valentina Bala, the author of this PhD-thesis, is a registered nurse, specialized in rheumatology, and has a Master degree in Nursing Science. She works as the head of the Department of Outpatient Care within the Area of Specialized Medicine at Helsingborg Hospital in Sweden. She teaches rheumatology nursing at graduate level and is co-author of the recently published book "Nursing and Medicine". For the past four years she has been the chairman of the Association of Rheumatology Nurses in Sweden.

The research within this thesis follows the author's interest in and contribution to implementing a nurse-led approach in outpatient rheumatology care. The thesis addresses the issue of measurement of person-centered care from the patient perspective as a means for further development and quality assurance of care in nurse-led rheumatology clinics.

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